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This study is a prospective study of women at high risk for early-onset breast cancer, and their husbands and siblings. Proband women are assessed at study entry, immediately before receiving results, and 2-, 6-, and 12-months after receiving results. Women who do not receive test results are assessed annually to track changes in functioning over time. The main objectives of the study are to describe psychological functioning among high-risk women and their families; evaluate the performance of screening instruments in detecting clinical depression; describe social support processes among high-risk women; and assess the impact of genetic testing on women and their families. We have continued our collaborations with the Cancer Risk Evaluation Program at the University of Pennsylvania to understand the impact of varying methods of result disclosure. Both baseline and follow-up data suggest that women and their families manage the process of genetic testing well, exhibit low levels of distress and worry, and report few negative effects of testing. Analyses are beginning to clarify predictors of health behaviors, risk perception, response to testing, and other indicators of adjustment. Future analyses will clarify causal relationships among personality and functioning, as well as the impact of different methods of receiving results.

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INTRODUCTION

This project was prospective study of women at high risk for early-onset breast cancer and their families. The project tracked four interrelated groups: (1) approximately 600 proband women who were among the first persons to have access to testing for alterations of the BRCA1 and BRCA2 genes and who were at risk for early-onset breast cancer based on having two or more family members affected by cancer; (2) the spouses of the approximately 400 women who are married; (3) a stratified random sampling of 120 of the women's unaffected sisters (those who have not been diagnosed with breast cancer); and (4) 80 brothers. Key variables included proband women and family members' stress and social support processes, including cancer-related stress and support; psychological distress and psychiatric morbidity; marital and family functioning; psychological characteristics presumed to affect the women's information-processing, decision-making, and subsequent adjustment; the at-risk women's intentions to seek predictive testing and anticipated outcomes and plans for use of the information; relevant attitudes, beliefs, and expectations; and current surveillance and adherence behaviors. Initial assessment of the proband women was by self-report questionnaires and telephone interviews. Subsequent reassessments of proband women's concurrent cancer-related stress, support and beliefs, attitudes and intentions, distress, and psychiatric morbidity were also by telephone interview and questionnaire. Husbands and siblings were assessed by self-report questionnaires. The proband women, spouses and siblings were reassessed as the option of predictive testing was made available to the individual women. A second reassessment of proband women occurred 8 weeks after test results were available. Follow-up assessments occurred at 6 and 12 months for women choosing to receive their genetic testing results, and yearly for women whose test results were not available or who chose not to receive them. The main objectives of the study were to describe psychological distress and psychiatric morbidity among high-risk women and their families, to evaluate the performance of screening instruments in detecting clinical depression, to describe social support processes among high-risk women, and to assess the impact of genetic testing on women and their families.

BODY

Background

Predictive testing is now available for mutations of both the BRCA1 and BRCA2 genes known to increase risk for breast and ovarian cancer and possibly other forms of cancer (e.g., prostate). Only about 5-10% of all breast cancers are believed to be hereditary in nature, but this figure could be as high as 20% for early onsetcancers. Furthermore, it is estimated that 15-45% of families with multiple cases of breast cancer, and as many as 80% of families with elevated rates of early-onset breast and ovarian cancer carry mutations of either BRCA1 or BRCA2. , These rates, however, may be somewhat lower in the general population than in the hereditary breast and ovarian cancer registries from which they were derived.

It has been estimated that female carriers of mutations in BRCA1 or BRCA2 have a 50-85% lifetime risk of developing breast cancer. Carriers of BRCA1 mutations have a 20-40% lifetime risk of developing ovarian cancer, while the risk associated with BRCA2 is slightly lower at 15-20%. Male carriers of these altered genes are at somewhat increased risk for prostate and colon cancer, and male carriers of BRCA2 have a 6% risk of breast cancer. Cancer susceptibility conferred by BRCA1 and BRCA2 mutations is transmitted as an autosomal dominant trait, meaning that the mutations can be inherited from either parent, and offspring have a 50% risk of inheriting the mutation. Options for women who carry a mutation include increased surveillance, prophylactic mastectomy or oophorectomy, and chemo-prevention. None of these measures is perfect, and all have known limitations, as recently noted by our investigator group (Eisen & Weber, 1999).

The current project has been tracking women and their families from well before genetic testing occurs to 12 months after receipt of results. Testing was offered to our research sample as part of a series of genetic linkage and mutation studies, and has now become available in the community. Approximately 1 in 1,000 people are carriers of BRCA1/BRCA2 mutations (Ford & Easton, 1995), and a higher proportion will face the dilemma of deciding whether to seek testing. BRCA1/BRCA2 mutations are the first mutations for which widespread genetic screening of asymptomatic persons for risk of late onset disease is appropriate, and the availability of testing raises daunting and largely unprecedented issues. Women with positive family histories of breast cancer have expressed considerable interest in obtaining predictive testing. Yet, little is known about the extent to which women who indicate they intend to obtain testing actually follow through with it. Furthermore, little is known about the benefits of knowing one's risk status , or about the psychological and social costs of having access to such information. Positive findings conceivably carry the threat of psychological and psychiatric morbidity for women and family members, the disruption of family relationships, and the impairment of the women's surveillance and adherence behavior. The degree of vulnerability, and factors which identify individuals and families at greatest vulnerability, however, have not been determined. Indeed, negative findings or deciding not to access risk status information concerning could also have detrimental effects on the women and their families.

In the absence of a large body of relevant prior research, we were faced with an urgent need for basic descriptive data concerning women at high risk for early onset breast cancer and their families. This includes their psychosocial assets and liabilities, attitudes and beliefs, intention to seek predictive testing, and preparedness for possible results. We have now collected a substantial body of descriptive data about women with family histories of cancer, and their experiences with genetic testing, and have been disseminating these data (Coyne & Anderson, 1999; Coyne, Benazon, Gaba, Calzone, & Weber, 2000).

Recognizing the opportunity to build on our extensive baseline assessment with prospective data, we instituted follow-up assessments at key points in the process of genetic testing. Now that the project has progressed to its final year, we are accumulating substantial follow-up data that allow us to track changes over time in participants' psychological and social functioning, cancer-specific perceptions and health behaviors, and other relevant factors. Our follow-up assessments also allow for describing how participants view the process of genetic testing, and the role that genetic testing has played in participants' lives. Furthermore, we have developed collaborative arrangements to ensure the predictive utility of our data in examining the long-term consequences of high-risk status and the availability of genetic screening to these women.

This project was a prospective study of high-risk women and their family members who were among the first to be offered testing for BRCA1 and BRCA2 mutations. We anticipated assessing 300 high-risk women, but have been able to expand recruitment to approximately 600 women, due to the expansion of the Hereditary Breast and Ovarian Cancer registry. Women participating in our study received in-depth baseline assessment by questionnaire and telephone interview. Initial assessments were started at the point of receipt of funding from the DoD. We sought additional funding through the Department of Defense Breast Cancer Initiative in order to complete initial assessments and to monitor women's progression through the process of genetic testing. We originally instituted assessments at 4 time points: when testing for BRCA1/BRCA2 became available to the women, within 8 weeks after receipt of results, and 6 and 12 months after testing.

Our sample is well described in terms of medical and family history. Our assessment instruments have immediate relevance to the planning and design of clinical protocols, as well as use in clarifying basic individual and family stress and coping processes. Variables assessed included attitudes and beliefs; personality traits; social support and family functioning; psychological distress and psychiatric morbidity; and decisions and behavior relevant to management of cancer risk. These measures will allow estimation of psychosocial costs, if any, associated with the offering of testing, and modeling of intention to obtain testing and subsequent decision-making and functioning. The resulting longitudinal data will have a direct application in estimating the need for services, refining appropriate clinical protocols, and suggesting requisite training for personnel providing services.

Additionally, given the importance of social support, and the recognition that testing may be an event for husbands and family, this project incorporated a protocol for assessments of the husbands and

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siblings of participating women. Husbands and siblings are assessed by questionnaire before the proband woman received her results, and reassessed at 6 months following the woman's receipt of results.

The first objective of this study has been to assess psychological distress, current and past psychiatric disorder, and functional impairment in women at high-risk for breast and ovarian cancer who are anticipating the prospect of genetic testing. Establishing base rates of distress and impairment permits us to evaluate the mental health needs of women anticipating testing, and serves as a first step in evaluating the incremental distress associated with receipt of results.

The second objective has been to compare women with previously diagnosed breast cancer to women who had not been affected at baseline. Initial differences between the two groups are important to evaluate the extent to which unaffected women subsequently develop characteristics like those of affected women upon receipt of findings that they carry the altered gene. On the other hand, it might prove to be the case that heightened awareness of high-risk status among unaffected women has already resulted in comparable levels of distress and disorder.

A third objective has been to describe social support processes among the women and their families.. We have been particularly interested in the involvement of husbands and female family members in women's decision making concerning cancer risk management and decisions about testing. Spouses are usually the most important source of support for married persons (Brown & Harris, 1978; Coyne & DeLongis, 1986), but the women in our study are members of high-risk families, with first-degree female relatives in similar predicaments. The support and information that close female relatives provide, how these relatives cope with their own dilemmas, and the decisions they make about testing are likely to have profound effects on the high-risk women. It may be that mobilization of social support around the shared risk of cancer results in female relatives having more influence on proband women than do spouses. An understanding of these support processes has practical importance in the design of educational, counseling, and follow-up protocols.

A fourth objective has been to track psychosocial changes across the process of being offered genetic testing. As a result of our ongoing assessment efforts, we have sufficient follow-up data to conduct initial longitudinal analyses, both for proband women and for their husbands and sisters, where applicable. These analyses will evaluate changes over time in psychological distress, breast cancer worry and worry-related functional impairment, risk perception, screening behaviors, and other relevant factors. We also now have rich descriptive follow-up data about the impact of genetic testing on the lives of high-risk women and their families.

Procedure and Accomplishments to Date

Years 1 & 2

W successfully met our objectives during the first two years of the study. Expansion of the Hereditary Breast and Ovarian Cancer Registry from which subjects are drawn allowed recruitment of a larger sample for than expected. This was fortuitous because preliminary testing of blood samples from

women already affected by breast and ovarian cancer in high risk families has now revealed that BRCA1 and BRCA2 mutations account for less familial breast cancer than predicted. At the present time, negative results are generally not informative for women from families without a known mutation of BRCA1 or BRCA2. Identification of a particular mutation in a family member affected by breast cancer is a prerequisite for informative testing of unaffected family members. The implications of this are that many female family members of women in our sample will not be offered testing unless a mutation can be identified in our study participants. As noted below, this may result in increased psychological burden on affected women seeking testing: Whether family members can be tested depends on their results. Our substantially augmented sample allows us, nonetheless, to have a more than adequate sample size and statistical power to examine women who progress to a choice about testing.

We began encountering delays in the offering of testing for a variety of technical and practical reasons during the second year. In response, and in anticipation of further delays, we designed an interim assessment to be administered if testing had not occurred within 1 year of baseline assessment. This interim assessment also served to reduce the burden of the baseline assessment by redistributing some of our trait measures. It also allowed re-administration of measures of distress and other state variables likely to fluctuate. As planned, women who progressed to the opportunity to get their results received these measures in their pre-counseling assessment. We also took advantage of a larger, long-term follow-up study that recruited women found to have a mutation of BRCA1 or BRCA2 from the Hereditary Breast and Ovarian Cancer Registry. Additionally, an international sample of persons, both male and female, who have been found to have a mutation was recruited and tracked. Although the long-term follow-up study was originally designed to track morbidity and mortality, we added a psychosocial component using instrumentation developed in our present project. Furthermore, for women from our present sample who continued to be followed we had the benefit of data collected prior to their being found to be carriers of a mutation. For some purposes these data will be separated for analysis, but for others they can be combined. This addition will very likely make our sample the largest database of women who have received genetic testing for risk of breast and ovarian cancer.

In our second year we continued data collection, refined our research objectives, and modified our instrumentation based on initial results. Our interim assessment allowed us to monitor state variables such as mood, and obtain additional trait measures for women having more than a year elapse between initial assessments and being offered testing. We also responded proactively to a number of difficulties, including a lower uptake of genetic testing than anticipated and a greater proportion of non-informative results. We enrolled additional women in the study as new participants were recruited to the larger Hereditary Breast and Ovarian Cancer Registry. As anticipated, women enrolled in our sample continued to receive the opportunity to obtain testing, and progressed to 6-month follow up during the second year.

Based on initial results, we adapted instrumentation to better accommodate women receiving uninformative results. For example, we refined our assessments of women's appraisals of the opportunity

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to obtain testing. Our scaling technique for this is an important methodological innovation in itself. We utilized our interim assessment of the women in our sample and the initial assessment of their husbands to explore the role of social support processes in resiliency. One hypothesis is that explicit awareness of the high-risk status of these families has led to the mobilization of support processes organized around this status. If this is so, women in the community seeking testing may not share this advantage. This should prove to be one of the many valuable points of comparison between our registry and community samples.

Year 3

During the third year of the project, we have continued to track women through the process of genetic testing, with some women now progressing to 12-month follow-up. Our recruitment and assessment of spouses and sisters has proceeded on schedule. We also submitted several manuscripts which have now been accepted for publication, focusing on psychological distress (Coyne, Benazon, Gaba, Calzone, & Weber, 2000), and social support (Coyne & Anderson, 1999). Copies of these manuscripts are included as Appendix C. We are in the process of analyzing data in preparation for a number of other manuscripts. One such manuscript expands upon the data presented in Coyne and Anderson, testing relationships between social support processes and psychological distress, and making use of the longitudinal data collected in this study. This project provides a unique opportunity to study the causal relationships among variables over time, in contrast to the majority of studies that are limited to making causal inferences from cross-sectional data. As more follow-up data become available, we intend to use causal modeling to clarify the temporal relationship between support and distress. Another set of analyses planned for publication involves describing perception of risk among women with a family history of cancer, and explaining how risk perception is formed and perhaps changed through the process of genetic testing. In a related study, we also plan to investigate the impact of genetic testing resulting in uninformative test results. Classic theory on predictive judgements (Rottenstreich & Tversky, 1977), the effects of framing on judgements (van Schie & van der Pligt, 1995), and preliminary data from the current study suggest that there may actually be a psychological cost of participating in genetic testing when results turn out to be uninformative. With the imminent release of a new batch of test results, we expect to be able to address this question.

In addition to the continued progress we have made in collecting and presenting data, we successfully responded to important structural and technical challenges, and created opportunities from these challenges that were previously not available to us. The key structural change this year was the transfer of the project from the University of Michigan to the University of Pennsylvania. Until this year, the research teams at the two institutions had been collaborating from a distance, with the biomedical research team located in Philadelphia, Pennsylvania, and the psychosocial research team located in Ann Arbor, Michigan. Shifting the psychosocial component of the project to Philadelphia has allowed for an integration of these two important and complementary aspects of genetic testing, and has generated a number of collaborative research projects that take advantage of the diverse areas of expertise of research

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team members, and substantially increase the utility of data we have been collecting from our registry sample.

One such project addresses the issues of selection bias and sample representativeness in the Hereditary Breast and Ovarian Cancer registry sample. One would expect that women who volunteer to participate in a cutting-edge research project such as this might be an especially motivated, persistent, well-adjusted, and socially-supported group. Indeed our data show that women in the registry sample are remarkably free of psychological distress and psychiatric morbidity, and were socially advantaged in terms of education, income, and marital stability. This is consistent with other reports of high-risk women in research and clinical protocols, and of research participants during the identification of genetic markers for Huntington's disease. Although highly-select registry samples have been well described, we know virtually nothing about women in the general community who are in the process of seeking genetic testing. With increasing media attention, the continued research into genetic markers for cancer risk, and the promise of potentially modifying cancer risk, more women from the general population may seek or be offered genetic testing. Together with an oncologist extensively trained in epidemiology and biostatistics, we are in the process of implementing a large-scale study comparing the unique women in our research sample with two groups of women from the community. One group will come from an NCI Program Project studying women in the community (Brian Strom, Prinicipal Investigator). In addition to capturing the experiences of women outside the highly-select registry sample, this project aims to describe the cancer risk experiences among African-American women who remain under-represented in the cancer registries.

Also, we are fulfilling our expectation for collaboration with University of Pennsylvania physicians, and recruiting a second group of women at high risk for cancer through the Cancer Risk Evaluation Program (CREP). Psychosocial and biomedical data from this study allows comparisons between the cancer risk experiences of women in our registry sample and women seeking clinical (rather than research) services through the CREP. We already have one paper in press, and have prepared another one concerning risk perception based on the CREP data (Coyne, Kruus, Racioppo, in press; Racioppo, et al., 2001).

Another project that developed as a result of our move to the University of Pennsylvania involves linking our psychosocial data with biomedical and other data for women participating in a randomized clinical trial of different methods of delivering genetic testing results. This project compares pre-test counseling and results disclosure by telephone with counseling and results disclosure conducted in-person at the physician's office. This study was instituted to address the inevitable changes in the genetic testing process as it moves from the controlled research setting to the larger community. This study aims to track the feasibility, acceptability, and effectiveness of different methods of delivering genetic testing services. Data from this new study links with the extensive baseline psychosocial data already collected as part of the present study. This linking of data gives us the opportunity to test an aptitude-by-treatment

interaction model (ATI), whereby specific participant characteristics are matched with particular types of interventions to achieve optimum effectiveness of services.

We are have expanded our Long-Term Follow-Up Study (LTF), begun as an adjunct to the current study. The LTF Study describes the long-term psychosocial functioning among women and men who have received genetic testing results through mechanism other than the University of Pennsylvania program.

Technical obstacles that began in the second year continued through the third year, resulting in delays in the actual availability of genetic testing results. Consultation with the University of Pennsylvania biomedical team suggested that the slow pace had been due in part to changing genetic testing technology. Specifically, laboratory technicians began to re-run assays to include an expanded range of exons, and began running southern blot assays on samples from families with low probability of mutations. We have been in close communication with the laboratory technicians and testing coordinator regarding these delays, and consequently anticipated a flood of requests for test results as these new testing procedures were completed and as women were notified that their test results are available. We also continued to describe the experiences of women who have not yet received results through yearly interim assessments.

In addition to technological challenges, it also became clear during the second and third years of the current study that women who had initially expressed interest in testing are requesting their results at a much lower rate than anticipated. The decision to accept testing is not a simple dichotomous one, with many women either failing to respond to the opportunity for testing, or deferring a decision to an unspecified later date. Some of this declining of testing is passive, with participants simply not responding to letters notifying them that their results are now available, or by their not returning consent forms. This is quite consistent with past experience with testing of persons at risk for Huntington's disease, but it remains an important phenomenon to study. Another investigator group has concluded that members of high risk families who decline testing in may suffer adverse psychological consequences (Lerman et al., 1997). However, we have shown that declining testing may represent a rational decision to defer testing when other stressors are present in women's lives (Coyne, Weber, & Sonis, 1999). We are currently refining a project that addresses such issues, and will specifically assess the experiences of women who have been offered testing but have not pursued receipt of their results. Our initial data provides us the opportunity to explore predictors of discrepancies between initial intention to obtain testing and actually pursuing receipt of test results.

Year 4

During the fourth year of the project, we continued ongoing data collection, and developed several adjunct projects to address areas of the genetic testing process that are not well understood. As part of our ongoing data collection, we continued to track women from pre-results through to post-results disclosure, as well as administering assessments to those women who still had not received test results. Women who

had received results during the previous year completed 2-, 6-, and 12-month follow-up assessments. Also, completion of testing for mutations in BRCA2, and re-testing of many samples using more precise assays made test results available to a large group of participants. Hence, we anticipated thatthe number of women progressing through to results-disclosure and post-results would increase dramatically this year. However, only a small proportion of women to whom results have been made available have actually followed through with receiving results.

Clarifying the reasons that participants have for not pursuing results is an important aspect of understanding the barriers to genetic testing, and the degree of interest in predictive testing for cancer. In Year 3 of the project, we mailed an interim assessment to each woman who had not received test results. In year 4 we mailed a second interim assessment to over 400 women who had still not received results. Adding these interim assessments to the thorough assessment completed at baseline, we now have longitudinal data spanning three years. This allows us to track any changes in intentions to get test results among high-risk women who have not requested results, and other psychosocial issues such as marital satisfaction, coping, and life events that may be barriers to the pursuit of test results. Additionally, we conducted scripted follow-up phone calls to assess more specifically why women had not pursued getting test results. This has allowed us to distinguish between true decliners of test results and those who simply had not followed-through with getting results because of misunderstandings about the process, having lost the materials, or other reasons. These follow-up phone calls also helped to clarify the next step for those women who wished to get test results.

As expected, our collaborations with the Cancer Risk Evaluation Program (CREP) at the University of Pennsylvania flourished this year. Together with the CREP group, we expanded the original WHS study to include comparison of different methods of conveying genetic test results. Specifically, this study compares participants' experiences with traditional results-disclosure by a local provider to results-disclosure by a cancer risk counselor via telephone. This study is based on the recognition that genetic testing is no longer conducted solely in the context of research studies in academic settings, but is being delivered in less structured ways (e.g., by telephone) in the community by general practitioners. This adjunct study allows us the opportunity to compare participant outcomes given different methods of results-disclosure. An added benefit of this adjunct study is that it allowed us to recruit new participants into our pre- and post-results assessments, increasing our study sample and including a small sample of male probands.

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Together with the CREP group, we produced several papers and presentations on the issue of risk perception and distress among higher-risk women seeking cancer risk counseling. Our research team presented two posters at The Eunice and Irving Leopold Annual Scientific Symposium and Retreat held in March, 2000 at the University of Pennsylvania, gave several paper presentations relating to psychological distress and the efficiency of screening measures, and submitted several empirical papers for publication in academic journals. Abstracts of these presentations, and copies of the manuscripts are included as Appendix C.

Year 5

During the fifth year of the project, we have continued to track the original participants' progress through the results-disclosure process, increasing data concerning participants who have progressed to post-disclosure follow-up. We have also added several components to our tracking system in order to explore hypotheses based on observations made during the standard data collection. One such observation was that a relatively small number of participants chose to pursue receiving their test results, despite having participated in the extensive baseline assessments and having donated blood samples as part of the project. Others in the genetic testing field have encountered similar patterns, and the common explanation is that participants are too distressed or anxious to follow-through with receiving test results. Given the relatively low rate of psychological distress in our sample, we hypothesized that other factors explain low uptake of results. We undertook a series of brief, structured phone interviews to explore the reasons for participants' decisions regarding genetic test results. The procedures and results of these interviews are presented in a following section, and the interview format is attached as Appendix B.

We have also added an exploratory interview of cancer risk perception among our participants. Estimates of cancer risk, both in the general population and in medical settings, are notoriously inaccurate. Results from different methods of assessing cancer risk are greatly discordant, and there is evidence that numerical estimates are flawed due to a lack of understanding of probabilities (a skill termed "numeracy" in the literature). Our assessments include several measures of cancer risk perception, and we have added a set of open-ended questions to our follow-up interviews (included as Appendix B) which ask participants to explain the thinking behind their numerical and comparative risk estimates. Although preliminary, participants' responses have provided some insight into the ways in which genetic testing participants conceptualize their cancer risk.

We have also continued our collaborations with the Cancer Risk Evaluation Program (CREP) at the University of Pennsylvania, and have expanded our data collection. Most importantly, we have worked

with the CREP team to study different methods of disclosing genetic test results. As genetic testing becomes more available in community medical practices, disclosure of test results has shifted from the formal counseling and follow-up sessions established for research protocols, to briefer disclosure procedures, sometimes even delivered via telephone. Our team has joined with the CREP team to study patients' experiences with the disclosure of genetic testing results via counselor and via telephone, assessing factors such as patient satisfaction with the process, understanding of test results, psychosocial response to the different result-disclosure procedures, and other factors.

Methods

Women and their families participating in this study were drawn from the Hereditary Breast and Ovarian Cancer Registry originally established at the University of Michigan, but now housed at the University of Pennsylvania. There were two sets of criteria by which women could be included in the registry: Unaffected women had at least two cases of either breast or ovarian cancer in their family, and affected women had at least one other affected family member. A periodic informational letter to women enrolled in the registry made reference to the possibility of an impending longitudinal study of them and family members. To recruit subjects for the psychosocial component of the University of Michigan/ University of Pennsylvania study, a cover letter, consent form, and questionnaire were sent to eligible enrollees in the registry. After the baseline questionnaire and consent form were returned, subjects were contacted by telephone in order to answer questions and schedule the telephone interview. If we received neither a questionnaire nor a mail-back refusal form, we called subjects, explained the details of the study, and offered to send another packet if necessary. At the point of actual receipt of funding, some of the women had already participated in the initial assessment and had been alerted to the possibility of their being asked to continue in a longitudinal study and to enlist family members. Women continuing to participate in the study were asked to solicit the involvement of spouses. Given the sensitive nature of risk information, concerns about confidentiality dictated that we ask the women themselves to contact family members, rather than contact the family members directly. We discussed the rationale with the women for their family members' involvement, underscored the voluntary nature of their choice whether to facilitate their family members' participation in the study, and if they so chose, ask them to provide names and permission to contact these relatives.

Our ability to track women and their families through the course of their being offered testing was largely dependent upon their actually being given the opportunity to obtain results, and on their pursuing receipt of results. As anticipated, another set of test results was made available to participants during this fifth year. Many of these participants were not part of the original Women's Health Study sample, but were recruited through an introductory letter that accompanied the notification of the availability of test results. Those agreeing to participate completed a thorough questionnaire that combined baseline and pre-

results information that original WHS participants had already completed. This new set of test results was also the basis of the collaborative study of different methods of disclosing test results introduced above. Registry participants (including both women and men) who had not been offered test results previously were invited to participate in this study. Participants were told that they would be randomized to receive test results either in the standard way (by meeting with a genetic counselor at the University of Pennsylvania or at a clinic they designate in their community), or that test results would be disclosed by telephone discussion with the staff at the University of Pennsylvania Cancer Risk Evaluation Program. Participants who consented to participate completed the combined baseline and pre-results questionnaire, and were then folded into the standard schedule of follow-up assessments (2-months, 6-months, and 12-months post-results disclosure assessments).

Measures

Our selection of measures meets or exceeds what was proposed in our original grant application. Copies of our battery of instruments are included as Appendix B. Table 1 lists the study's main measures for proband women and their husbands.

Table 1

Selected Assessment Measures

PROBAND MEASURES		
Questionnaire	Interview	Interim Assessment
Demographics	Contextual Rating of	HSCL-25, MOS-36
Health Locus of Control	Cancer Threat:	Cancer Worries
Risk Perception	Affected Relatives	FAD, Short-Form DAS
Intention to Seek Testing	Relationship to	Quality of Social Support
Knowledge, Beliefs and Attitudes	Proband	Life Cycle Issues
Reasons for Seeking Testing	Outcome	Receipt of Individual,
Cancer Worries	Involvement of	Group, & Family, Counseling & Education
Stressful Life Events	Proband In Care	
Optimism (LOT)	Effects on Proband's	COPE
Miller Behavioral Styles Scale (MBSS)	Life	Relationship-Focused Coping
Hopkins-25, MOS-36, AUDIT	SCID Depression , Anxiety, & Substance Use Modules	CBCL
Dyadic Adjustment (DAS)	Cancer-Specific Support Processes	Evaluation of Preventive
General Family Functioning (FAD)		Options
Social Support & Cancer-Related Support Processes		

HUSBAND QUESTIONNAIRES

Demographics	COPE	Stressful Life Events
Health Locus of Control Risk	Knowledge, Beliefs and Attitudes	Coping Behavior Checklist
Perception	Anticipated Reactions	LOT, MBSS, HSCL-25,
Worries About Wife's	Social Support & Cancer-Related	SF-36
Risk of Cancer	Support Processes	AUDIT
Preference for Wife's Testing		DAS, FAD
Relationship-Focused Coping		

Sample

Table 2 presents basic demographic data on the proband women in this study. They are similar to other samples of persons seeking genetic services in that the majority is married, relatively well-educated, and earn fairly high incomes.

Table 2

Basic Demographic Data

	ALL WOMEN	UNAFFECTED WOMEN	AFFECTED WOMEN
Age	48.52	46.32	51.61
	(12.07)	(12.14)	(11.48)
Religion:			
Christian	76.3%	80.2%	71.4%
Marital Status:			
Married/with partner	80.3%	78.6%	82.6%
Number of Children	2.09	1.99	2.25
	(1.38)	(1.40)	(1.33)
Education:			
At least some college	75.5%	80.5%	81.6%
Employed Outside Home	63.2%	64.5%	61.0%
Annual Household Income	$50,000+	$50,000+	$50,000+

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During Year 5 of this study, an additional 25 women completed the combined baseline/pre-results assessments as part of the results-disclosure study. Of the total sample, now 610, 46 have received test results and completed the first phone follow-up assessment. lightly less than half (46%) of the overall sample have a personal history of breast cancer. Thirty-seven percent of participants have progressed to the second follow-up assessment, and a total of 33 participants have completed the 12-month follow-up assessment.

Psychological Distress

This study included several measures of psychological distress, including the 25-item version of the Hopkins Symptom Checklist (HSCL-25), single items assessing cancer-specific worry and related functional impairment, and the intrusion subscale of the Impact of Events Scale (IES). The HSCL-25 (Derogatis et al., 1974) is highly correlated with the standard 58-item version (Heshbacher, Downing, & Stephansky, 1978), and has a better balance of sensitivity and specificity than a number of other screening instruments such as the CES-D (Heshbacher et al. 1978; Hough et al. 1982). There is extensive data using this scale with healthy, physically ill, and psychiatric samples (Cohen, Coyne, & Duvall, 1993; Coyne & Smith, 1991; Coyne & Sonnega, 1995, Pepper, Coyne & Cohen, 1996).

In previous years we have described results related to psychiatric morbidity and the performance of screening instruments in making accurate psychiatric diagnoses. In these initial analyses, the HSCL-25 served as the measure of distress and a telephone interview using modules of the SCID served as the measure of current and lifetime psychiatric morbidity. We found surprisingly low levels of psychological distress, and even lower levels of psychiatric disorder. In the second year, we modified our earlier results based on continued accrual of subjects, although the pattern of remarkably low distress and psychiatric morbidity remained. In general, both affected and unaffected in our sample are remarkably free of distress. Table 3 presents mean HSCL-25 scores and percentages of women meeting or exceeding the clinical cut-off for depressive symptomatology. Because there were no significant differences between affected and unaffected women, HSCL-25 scores are collapsed across the entire sample.

Table 3

HSCL-25 Psychological Distress

	BASE-LINE	INTERIM 1	INTERIM 2	PRE-RESULTS	POST-RESULTS 1	POST-RESULTS 2	POST-RESULTS 3
HSCL - 25	37.56	37.01	37.79	36.34	41.53	34.4	36.26
	(9.15)	(9.04)	(9.21)	(10.46)	(12.14)	(13.95)	(10.34)
% Above Clinical Cutoff of 43	21.2%	20.2%	19.7%	20.7%	27.6%	17.3%	26.4%

The finding that one-fifth of women met or exceeded the clinical cut-off led to two follow-up studies. The first involved a set of analyses assessing the performance of screening measures in predicting clinical disorder among a subsample of the participants. Specifically, we compared rates of lifetime depressive disorder according to a diagnostic interview (SCID) with two self-report screening measures of history of depression of 323 study participants. One measure was a simple self-report of history of 2-weeks mood disturbance with or without functional impairment. The second self-report measure was the HSCL-25. The results of these analyses are reported in an article that is in press at the Journal of Psychological Assessment (Coyne, Thompson, & Racioppo, 2000).

According to the SCID interview, 66 (20%) of the women had a history of depression. The simple self-report concerning past two weeks mood disturbance yielded a much higher number of women reporting a history of depression (179, or 55%). Not only were the estimates of prevalence vastly different between semi-structured interview and simple self-report, but there was not significant overlap between semi-structured interview and simple self-report in terms of who had a history of depression and who did not, χ^2 (1, $\underline{n}$= 323) = .33 n.s. The correspondence between self-report and structured interview of history of depression is shown in Table 4. It is noteworthy that only 52% of the women who had been found to have a history of depression in the interview reported a lifetime two-weeks mood disturbance in the later self-report assessment. Specificity for the simple self-report was a modest 44 % and sensitivity was even worse (52 %). Positive predictive value was only 19%.

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Table 4

Correspondence Between Self-Report and Structured Interview
of History of Depression.

	SCID-Diagnosed Lifetime MDD	
Self-Reported Mood Disturbance	No History	History
No History	112	32
History	145	34

Women who had reported a past episode of depression in the SCID interview were more likely to be

distressed, according to a standard cut score of 44 on the HSCL-25, than were women who had not

reported prior depression, χ^2

The second follow-up study involves predicting clinical disorder, given that screening instruments

are not efficient at doing so. Recently published studies suggest that depressive symptoms in response to

stressful events (such as cancer or genetic testing for cancer) can be explained in large part by accounting

for past history of depressive episodes (Maunsell, Brisson, & Deschenes,1992; McDaniel, Musselman, &

Nemeroff,1997; Schover, 1991). Because so few participants met criteria for current major depressive

disorder in this study, there is not enough power to test the hypothesis that past major depressive

episode predicts future episodes with the current sample. However, this study provided pilot data that

allowed us to apply for additional funding from several other granting agencies, and we anticipate a

positive review of a grant specifically focused on testing past depression as a predictor of subsequent

depressive episodes.

The Women's Health Study also included several items commonly used to assess breast-cancer specific distress among genetic testing participants. These common measures assess the degree to which participants worry about breast cancer, the degree to which these worries interfere with their daily lives, and distress in response to cancer- or risk-related events (i.e., being a member of a family with a cancer history, being offered genetic testing, and the possibility of being told that one is positive or negative for a genetic mutation). As Table 5 illustrates, while women report moderate levels of breast cancer worry on average, they report little to no functional impairment due to these worries.

Table 5

Cancer-Specific Worry

1= Not at All, 5= All the Time	BASE-LINE	INTERI M 1	INTERI M 2	PRE-RESULTS	POST-RESULTS 1	POST-RESULTS 2	POST-RESULTS 3
How often do you worry about developing breast cancer?	2.87 (.98)	2.74 (.99)	2.17 (1.02)	2.59 (1.12)	2.74 (.99)	2.43 (.93)	2.58 (.90)
To what extent do these worries interfere with your every day life?	1.65 (.92)	1.47 (.76)	1.48 (.65)	1.87 (1.22)	1.47 (.76)	1.38 (.59)	1.32 (.75)

Often, strong conclusions are drawn based on the responses to these items, relying solely on face validity because the concurrent or predictive validity of the items has not been established. Our study allows a test of the validity of these items by comparing these items to responses on standardized measures. Risk- and cancer-related distress and interference due to cancer worries were compared to several standardized measures of general distress and social/emotional health including the HSCL-25 and several functioning sub-scales of the Medical Outcomes Study, Short Form-12 (Ware, Kosinski, & Keller, 1996). The results are reported in a manuscript submitted to an academic journal for review (Coyne, Kruus, & Racioppo, 2001). In this study a series of 2 (cancer history) x 5 (level of distress for a given threat) ANCOVAs were conducted with HSCL-25 and SF-36 as the dependent variables, controlling for age. Importantly, results were consistent across these tests, indicating that distress ratings for risk- or

cancer-related threats were not associated with general distress or maladjustment. Even those women endorsing the highest level of distress from specific threats fell below the cut-point for clinically significant distress on the HSCL-25, and above the norm for social and emotional health and role functioning on the SF-36. The only exception was in the general distress analysis of threat related to testing negative for a BRCA1/BRCA2 mutation (F [4,96] = 2.88, p < .05). Follow-up analyses showed that women without a cancer history who reported very low levels of distress and scored significantly higher on the HSCL-25 ($\underline{M}$= 44.62) than similar women reporting no distress from testing negative for a mutation ($\underline{M}$ = 36.64; F[1,86] = 10.30, $\underline{p}$ < .01).

The Intrusion sub-scale of the Impact of Events Scale (IES, Horowitz, Wilner, & Alvarez, 1979) was included in the 2-month post-results telephone assessment to indicate distress related to receiving genetic testing results. The IES is often used in cancer risk studies, with a wide range of mean scores. For instance, studies of participants in cancer risk-counseling (Lerman et al., 1995; Lloyd et al., 1996) find low rates of intrusive thoughts. Mean intrusive thought scores are comparable for the WHS sample, which is well-below the cut-point suggested by the developers of the scale. As Table 6 indicates, on the whole, it does not appear that receipt of test results leads to excessive cancer-specific worry.

Table 6

Cancer-Specific Worry

	WHS 2-month Post-Results	Cancer Risk Counseling Participants (Lloyd et al., 1996)	Cancer Risk Counseling Participants (Lerman et al., 1995)
IES Intrusive thoughts Mean (SD)	6.22 (7.54)	6.9 (7.4)	3.6 & 7.5 (4.6 & 6.9)

Interest in Obtaining Testing

Table 7 presents data concerning the intention to receive testing when it is offered. As can be seen, the majority of women expressed an interest in obtaining results when assessed at baseline.

Table 7
Intention To Receive Test Results

	TOTAL SAMPLE
Definitely Will Receive Results	68.4%
Probably Will Receive Results	20.1%
Undecided	7.5%
Probably or Definitely Will Not Receive Results	4.1%

Now that test results have been made available to much of the sample, we are able to assess the degree to which intentions to pursue testing expressed at baseline predict actual receipt of results. A t-test found that women who actually received results as of Year 4 of the study were significantly more likely to report intentions to receive results than women who did not receive their test results (t = -2.33, p = .02). However, expressing the intention to get test results did not significantly predict actual receipt of test results. Collapsing across the "definitely" and "probably" responses at each end of the intention continuum, and excluding the ambiguous "undecided" response yielded a positive predictive value (PPV) of 12%, and a negative predictive value (NPV) of 95%. According to these results, only 12% of women expressing the intention to get test results actually do so by Year 4, although it is very likely that expressing a an intention not to receive results will be followed through.

Table 8 provides data concerning the women's reasons for obtaining test results. It appears that women with and without a personal history of cancer diagnosis seek genetic testing for different reasons. Women without a personal history of cancer are significantly more likely than affected women to seek testing for most reasons, including those related to planning for the future, modifying screening behavior, and reducing uncertainty. While both affected and unaffected women reported seeking testing to clarify their children's cancer risk, women with a personal history of cancer were significantly more likely to be motivated by this factor. This result is consistent with our anticipation of the salience of such family issues in the reasons for undergoing testing. Moreover, now that it has been decided that testing is appropriate for unaffected women only when they are members of families with known mutations, the saliency of family issues for affected women is likely to increase.

Table 8
Reasons For Seeking Testing

	ALL WOMEN	UNAFFECTED WOMEN	AFFECTED WOMEN
To Plan for Future	37.9%	51.0%	23.7%***
To Reduce Uncertainty	53.4	66.7	40.0***
To Be More Careful About BSE	30.7	40.4	19.5***
To Decide About Prophylactic Surgery	34.5	44.0	23.0***
To Decide About Family Planning	6.7	11.0	2.4**
To Assess Risk To Children	53.2	46.8	57.8***
Family Urges Testing	12.8	12.0	13.2

*p < .05   **p < .01   ***p < .001

Reasons for NOT pursuing receipt of test results

As described above, participants who had not yet pursued receipt of test results were contacted by phone to ascertain the reasons contributing to their decision. In total, 44 participants who had been sent letters notifying them of the availability of results, but who had not yet pursued results-disclosure were contacted. Of those contacted, 4 (9%) said that they had decided not to pursue disclosure of their genetic test results, 2 of whom said that their decision was partly due to being afraid of having a mutation, and 1 who said that she had already been diagnosed with cancer, but would still like to help in the study. A total of 22 respondents (50%) said that they were planning on getting their test results, but sometime in the future. Of these, 6 reported being too busy, 3 reported being afraid of being told of a mutation, 3 reported feeling overwhelmed by the experience, and 1 wanted to clarify the potential for health or life insurance problems related to testing. An additional 5 participants (11%) said that they were still undecided about whether or not they would pursue the results of their genetic testing. Although based on

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a small sample, these responses may suggest that anxiety about the possibility of being told one has a mutation is only one of many reasons that participants did not pursue receipt of test results.

Perceived Risk of Breast Cancer

Table 9 summarizes women's perceived risk of breast cancer assessed at baseline and again 6 months after results-disclosure. Consistent with findings from other registry samples (Lerman, Kash, & Stefanek, 1994), women in this sample perceived their risk for breast cancer as fairly high, averaging about 50% lifetime risk. We compared women's subjective risk perception with objective risk estimates derived from the Claus model (Claus et al, 1994), which predicts lifetime risk by accounting for cancer occurrence and age of onset in first-degree and second-degree relatives. Claus estimates are only estimated for unaffected women, because lifetime risk estimates among women with a personal history of cancer are not meaningful. On average, women significantly overestimated their perceived risk of cancer relative to objective Claus risk estimates, which averaged 22.55% (SD = 10.77), and ranged from 8.30% to 48.40%.

At baseline, women with a personal history of cancer perceived themselves as significantly less likely to get cancer than unaffected women, both in the near future and over their lifetimes. When assessed again at 6 months after receiving test results, affected women perceived their risk of developing cancer in the near future as greater than they previously had. Also, unaffected women's perception of cancer risk seemed to decrease over time, while affected women's perception of risk increased over time. As more women reach the follow-up assessment, we will have the statistical power necessary to determine whether this finding has meaningful implications for high-risk testing and counseling.

Table 9

Perceived Likelihood Of Breast Cancer Among Women in the Research Registry

	Baseline		
	All Women	Unaffected Women	Affected Women
In the Near Future	35.77%$_a$	44.6%***$_c$	27.7%***$_e$
In Lifetime	48.1%$_b$	54.7%***$_d$	39.38%***
	6 Months Post-Results		
	All Women	Unaffected Women	Affected Women
In the Near Future	39.1%$_a$	38.2%$_c$	42.2%$_e$
In Lifetime	45.2%$_b$	44.6%$_d$	48.9%

***p < .001;
Values with same subscript are significantly different at p < .05

Our closer proximity to the CREP group at the University of Pennsylvania has offered the opportunity to compare our research sample to a large sample of high-risk women seeking cancer risk counseling through the CREP clinic. A collaborative manuscript recently submitted to Cancer Epidemiology, Biomarkers, and Prevention described risk perception among this large clinic sample. Similar to the research sample, women in the clinic sample largely overestimated their lifetime numeric risk, averaging 49.1% (SD = 32.7). A paired t-test yielded a significant difference between objective risk estimates ($\underline{X}$ = 26.0%, SD = 17.4) and numeric risk perception ($\underline{t}$ = -8.07, $\underline{p}$ < .00).

Additionally, we investigated the relationship between risk perception and distress among both the research and clinic samples. Among the research sample, correlations between perceived risk of developing breast cancer and HSCL-25 psychological distress were modest but significant ($\underline{r}$ = 12, $\underline{p}$ < .05, for lifetime risk). Similarly, among the clinic sample, correlations between breast-cancer specific worry (as assessed by the Impact of Events Scale, Horowitz, Wilner, & Alvarez, 1979) and risk perception were modest but significant (r = .26, $\underline{p}$ < .00). These results are especially important because the current literature assumes that overestimation of cancer risk signals risk for psychological distress, and that accurate numeric risk information is an antidote for apparent catastrophizing about breast cancer risk. However, despite the large overestimates of numeric risk reported by women in both the research and clinic samples, women did not report high levels of psychological distress, and distress was only moderately related to measures of risk perception.

Husband Functioning

Table10 summarizes husband's reports of functioning at baseline assessment and at approximately 8 months after their wife-probands received genetic test results. Because of small sample sizes for follow-up, comparisons between time points should be considered tentative, but we anticipate a significant increase in husband follow-up assessments as the number of women seeking testing increases with the release of a large number of test results. Recognizing their limitations, this initial data seems to suggest that husbands report fairly low and stable levels of psychological distress and worry related to their wives developing breast cancer. Husbands' perceptions of their wives' lifetime risk of breast cancer appear to decrease after testing, although it remains to be seen whether this decrease is statistically significant, or perhaps more importantly, whether it is clinically significant.

Table 10

Husband Functioning at Baseline and Follow-up Assessments

	Baseline	8-Month Follow-Up
Psychological Distress	34.74	38.08
(HSCL - 25)	(7.94)	(7.85)
Worry about Wife Developing Breast Cancer	2.85	2.23
(1= Not at all, 5= All the time)	(1.17)	(1.01)
Interference from Breast Cancer Worries	1.78	1.38
(1= Not at all, 5= All the time)	(.06)	(.77)
Perceived Short-Term Risk of Wife Developing Breast Cancer	23.80%	26.92%
	(24.00)	(19.32)
Perceived Lifetime Risk of Wife Developing Breast Cancer	36.62%	29.23%
	(28.65)	(20.60)

Husbands also responded to questions about discussions with their wives about cancer risk and genetic testing. On average, husbands reported that their wives rarely seek support from them regarding cancer risk, and that husbands feel that this poses very little burden. Husbands also report the frequency with which they discuss genetic testing with their wives ranges from sometimes to often. Over half of husbands report that their wives initiate these discussions, while about a quarter of husbands report that they and their wives initiate these discussions equally often, and about one-fifth report that they themselves initiate these discussions.

Couple Functioning

The literature addressing couples managing chronic or serious illness often concludes that couples function as a unit, sharing attitudes about risk, being equally distressed and impaired by illness, and being equally involved in preventive and treatment decisions and procedures. One problem with this literature, though, is that most studies of couples facing illness have traditionally focused on male patients and their wives. The Women's Health Study presents a unique opportunity to test the process of couples coping with illness when the wife is the identified patient or proband. Given the findings of the general marital literature, including sex differences in coping, the experience of affect, and approach to problem-solving, it may be that female patients and their husbands respond to illness differently than male patients and their wives.

To explore these questions, we compared women-probands' risk perception, psychological distress, risk-related impairment, and involvement in risk-related activities to those of their husbands. Table 11 summarizes these comparisons. Level of worry about the development of breast cancer was not significantly different between participants and their husbands , however the level of interference in daily life caused by the worry was significantly greater for husbands. Further, husbands reporting less general psychological distress. Finally, these data show that husbands report a significantly lower perception of their wives' breast cancer risk than the women participants. These data suggest that couples in which the female is the identified participant may manage illness-related events differently than couples in which the male is the identified participant.

Table 11

Responses to Testing of Proband-Women and their Husbands

	Proband Women	Husbands	p	t
Psychological Distress	37.41	34.74	.001	.3.45
(HSCL - 25)	(9.04)	(7.94)		
Worry about Developing Breast Cancer	2.81	2.83	ns	-.21
(1= Not at all, 5= All the time)	(.97)	(1.17)		
Interference from Breast Cancer Worries	1.47	1.78	..00	-3.90
(1= Not at all, 5= All the time)	(.75)	(.89)		
Perceived Lifetime Risk of (Wife) Developing Breast Cancer (0 – 100%)	49.52% (31.11)	37.29% (28.12)	.00	5.08

Sister Functioning

Women participating as probands in the Women's Health Study were asked to consent for us to contact their sisters, both before and after results-disclosure. (what percent of those with sisters consented?) Table 12 summarizes several key aspects of sister-reported functioning. At both assessment points, sisters reported relatively low levels of psychological distress. Before results-disclosure, only 8.6% of sisters reported distress exceeding the standard cut-off of 44 on the HSCL-25. After results-disclosure, only 6.7% exceeded the standard cut-off.

Table 12
Sister Functioning at Baseline and Follow-up Assessments

	Baseline	8-Month Follow-Up
Psychological Distress	36.14	37.00
(HSCL - 25)	(10.35)	(6.00)
Worry about Developing Breast Cancer	2.74	2.47
(1= Not at all, 5= All the time)	(1.11)	(1.25)
Interference from Breast Cancer Worries	1.35	1.40
(1= Not at all, 5= All the time)	(.69)	(.63)
Perceived Risk of Developing Breast Cancer Relative to the Average Woman	3.79	-----
(1= Much lower, 5= Much higher)	(1.24)	

On average, sisters reported that their proband-sisters sometimes seek support from them regarding cancer risk, and that sisters feel that this poses very little burden. Sisters also report that they discuss genetic testing with their proband-sisters sometimes, and that these discussions are somewhat satisfying. Over two-thirds of sisters report that they and their proband-sisters initiate these discussions equally often, while one-fifth report that their proband-sister initiates discussions.

Social Support
In addition to assessing the functioning of husbands and sisters of proband women, we also asked probands about their social relationships and the degree to which friends and family are involved in the process. Overall, probands generally rated spouses as most important and involved in the process. The only exception to this is that probands were equally satisfied with discussions with their spouse and sister (F(1,240) = 0.20, ns). Table 13 summarizes these results.

Table 13

Family Involvement in Genetic Testing

1 = Never 2 = Rarely 3 = Sometimes 4 = Often				
Question	Spouse	Mother	Sister	Daughter
1. How often do you discuss your risk for breast cancer/living with breast cancer with your ___?	2.86 a,b	2.43 b	2.58 a	---
2. How satisfied are you with these discussions?	3.23 c	3.05 c	3.18	---
3. Overall, how important is your ___'s opinion in your decision whether or not to be tested for the breast cancer gene?	2.80 d,e,f	2.29 d	2.37 e	2.38 f
4. In making decisions about what to do to reduce your risk of breast cancer in the future, how important is your ___'s opinion?	3.02 g,h,i	2.47 g	2.47 h	2.53 i

Values the same subscript 'a' are significantly different from one another at $p < .01$
Values with the same subscripts ranging from 'b' through 'I' are significantly different from one another at $p<.001$

Probands also described who initiates discussions of cancer risk., as seen in Table 14. This is consistent with husbands' own reports of risk discussions with their proband-wives. About half of probands report that they initiate discussions with their mothers, and about one-fifth report that mothers initiate risk discussions. Similarly, a little less than half of probands initiate risk discussions with sisters, and a little less than half of probands report that they and sisters initiate discussions equally. This contrasts with sisters' own reports, where over two-thirds said that they and their proband-sisters initiate discussions equally often.

Table 14

Initiation of Discussions of Cancer Risk

	Percentage of Time Each Party Initiates Discussions of Cancer Risk?		
Specific Other	Proband	Other	Equally
Spouse	79.4	4.1	16.5
Mother	53.8	21.8	24.4
Sister	42.8	15.5	41.7

Finally, probands described the level of social support that they have received from their spouse/partner, a female family member at risk for breast cancer, as well as other friends. These results are

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presented in Table 15. Most probands reported receiving high levels of social support from female family members who were at risk for breast cancer, from spouse/ partners, and friends. The forms of social support included being available, offering advice, comfort, and reassurance, and listening to private concerns. The level of spousal support was especially high among this group as all probands reported that their partners were physically present when they were needed, were willing to assist in day to day tasks, and comforted them by demonstrating physical affection.

Table 15
Social Support Provided by Others

	Percentage of Probands Reporting to Receive Support from Each Source		
	Female Family Member at Risk for Breast Cancer	Spouse/ Partner	Another Friend
Was physically present when you needed	66.7%	100%	70.6%
Told you what he/she did in a similar situation.	60.0	46.2	56.3
Did activities to help get your mind off of things.	50.0	100	58.8
Told you that the things you talk about are private – just between the two of you.	26.7	57.1	46.7
Suggested some action you should take.	62.5	71.4	50.0
Comforted you by showing you physical affection.	40.0	100	40.0
Listened to you talk about your private feelings.	68.8	92.9	75.0
Agreed that what you want to do is right.	93.3	92.3	86.7
Told you how he/she felt in a similar situation.	73.3	53.8	60.0
Let you know that he/she will always be around if you need assistance.	88.2	100	81.3
Gave you feedback on how you were doing without saying if it was good or bad.	50.0	85.7	53.3
Pitched in and helped you do the things that needed to get done.	75.0	100	53.3
Intruded into your personal feelings and concerns.	6.3	14.3	6.7
Gave you unsolicited advice.	25.0	42.9	25.0
Attempted to make unwanted contact.	6.3	7.1	0.0
Discouraged you from discussing your feelings and concerns.	0.0	0.0	0.0
Rejected you for displaying emotional upset.	16.7	21.4	17.6
Minimized your worries or concerns.	5.6	0.0	0.0
Insisted that you remain upbeat and optimistic.	11.1	14.3	17.6
Let you down when you were counting on him/her.	5.6	7.1	5.9

Interim Assessments

In response to delays between baseline assessment and actual receipt of test results, we added a yearly interim assessment to our already comprehensive schedule of follow-ups. In this fourth year of the project, we completed another interim assessment for women who had not yet received their test results.

The main purpose of the interim assessment was to continue to monitor women's experiences with the genetic testing process, and to ensure that we had up-to-date measures of areas of functioning that might change over time (i.e., states rather than traits). Additionally, the interim assessments allow us to test hypotheses regarding causal relationships between variables, instead of relying on inferences from concurrently-collected data. Finally, these repeated measures allow us to explore psychometric issues, such as the stability and reliability of constructs and measures over time.

Like the investigator team, many women who joined the cancer registry, and specifically this study of the genetic testing process, did not anticipate that the process would take so long. One important question addressed by the interim data is the psychological impact this delay in testing has had on women. Table 16 compares key indicators of functioning of proband women annually from baseline to the second interim assessment. Of particular interest are the findings that the delay in testing does not appear related to increased psychological distress, so that a long delay between the possibility of testing and availability of results does not appear to lock women in a long-term stressful experience. Finally, level of optimism, intention for testing is fairly stable over the waiting period, suggesting that women did not appear to get discouraged from testing because of unexpected delays in the availability of results.

Table 16

Functioning at Baseline and 2 Yearly Interim Assessments

	Baseline	Interim 1	Interim 2
Psychological Distress (HSCL-25)	37.56	37.01	37.79
	(9.15)	(9.04)	(9.21)
Breast Cancer Worry (1= Not at all, 5= All the time)	2.87	2.74	2.17
	(.98)	(.99)	(1.02)
Interference from Worry (1= Not at all, 5= All the time)	1.65	1.47	1.48
	(.92)	(.76)	(.65)
Intention for Seeking Testing (3= Definitely, 2= Probably, 1= Undecided, 0= Definitely not)	2.53 (.80)	2.37 (.84)	2.20 (.99)
Importance of Health (Range 4 – 20)	14.60 (3.52)	14.95 (3.31)	13.92 (4.41)
Life Events (Number of life events)	1.01 (1.21)	.82 (1.09)	.89 (1.05)
Optimism (Life Orientation Test)	41.81 (9.96)	42.87 (9.64)	43.40 (9.35)

Impact of Genetic Testing

As more women are being offered test results, we are beginning to accrue more follow-up data describing women's experiences with genetic testing. As shown in Table 17, women rated the impact of testing on their lives, including their work and family lives, as largely positive. The impact of testing on women's work was significantly less positive than its impact on other areas of their lives.

Table 17

Impact of Genetic Testing at 6-Month Follow-up (Interview)

1= Very negative effect, 3= No effect, 5= Very positive effect	All Women	Uninformative Results	Negative for known mutation	Positive for known mutation
Effect of testing on your family	3.43 (.69)	3.50 (.64)	2.5 (.71)	3.43 (.79)
Effect of testing on your work	3.05 $_a$ (.41)	3.07 (.38)	2.50 (.71)	3.14 (.38)
Effect of testing on your concerns for child's future	3.46 (1.06)	3.54 (1.07)	2.00 (.00)	3.33 (1.03)
Overall effect of testing on your life	3.51 (.69)	3.57 (.63)	3.00 (.00)	3.57 (.98)

$_a$ Significantly different from other areas at $p < .05$.

Additionally, women described their psychological distress at two time points after results-disclosure, and the degree to which they regret participating in genetic testing (see Table 18). Women report little distress in response to receiving test results, and report little regret for participating in testing. Notably, women receiving uninformative results appear to report the highest levels of distress and regret, although small sample sizes make statistical comparisons inconclusive at this time.

Table 18

Responses to Genetic Testing at 6-Month and 12-Month Follow-ups (Questionnaire)

6-Month Follow-Up

	All Women	Uninformative Results	Negative for known mutation	Positive for known mutation
Distress Upon Receiving Results (1= Not at all, 5= Very distressed)	2.08	2.25	1.5	1.25
	(1.41)	(1.48)	(.71)	(.25)
Regret Decision to Be Tested (1= Not at all, 5 = Very much so)	1.29	1.35	1.00	1.00
	(.86)	(.93)	(.00)	(.00)

12-Month Follow-Up

	All Women	Uninformative Results	Negative for known mutation	Positive for known mutation
Distress Upon Receiving Results (1= Not at all, 5= Very distressed)	1.88	1.90	1.00	1.75
	(1.33)	(1.41)	(.00)	(.96)
Regret Decision to Be Tested (1= Not at all, 5 = Very much so)	1.16	1.19	1.00	1.00
	(.62)	(.68)	(.00)	(.00)

KEY RESEARCH ACCOMPLISHMENTS

As of this report, our research has yielded the following interesting findings:

- ✧ Women from registry samples participating in genetic testing appear to have higher incomes, more education, and more stable marriages than the general population.
- ✧ Participants in genetic testing for cancer risk appear to have low levels of psychiatric morbidity or clinical disorder.
- ✧ Psychological distress is not a useful predictor of clinical disorder.
- ✧ Retrospective reports of depressive episodes more accurately reflect current mood than history of depressive episodes.
- ✧ Women participating in genetic testing for cancer risk tend to greatly overestimate their breast cancer risk.
- ✧ Overestimates of cancer risk are not highly related to psychological distress.
- ✧ Different ways of assessing risk perception yield different responses, although these responses are all equally correlated with distress.
- ✧ Women with and without a personal history of breast cancer have different motivations for pursuing genetic testing.
- ✧ Common ways of assessing breast cancer worry are not highly related to standard measures of clinical disorder, functional impairment, or psychological distress.
- ✧ Women with and without a personal history of breast cancer are differentially affected by the process of genetic testing.
- ✧ Women with a personal history of breast cancer who report better marital adjustment tend to also report more positive outcomes in terms of general health and physical functioning, social functioning, and psychological functioning.
- ✧ Husbands of women anticipating genetic testing for *BRCA1/2* generally do not report clinically significant levels of distress.
- ✧ Women undergoing genetic testing for *BRCA1/2* report higher levels of psychological distress than their husbands.
- ✧ Perceived risk of developing breast cancer is significantly greater for women undergoing genetic testing than their husbands' perception of their risk.
- ✧ Husbands play a primary role in social and decision-making support for their wives who are undergoing genetic testing for *BRCA1/2*.

REPORTABLE OUTCOMES

The following manuscripts and have been published, or submitted for publication, based on data from the current study:

Coyne, J.C., Palmer, S.C., Kruus, L.K., Ten Have, T.R. Fundamental issues raised by the Classen et al. study. Archives of General Psychiatry. Submitted.

Coyne, J.C., Kruus, L.K., & Racioppo, M.W. (Submitted for publication). What do ratings of cancer-specific stressors mean among high risk women anticipating testing for BRCA1/ BRCA2? American Journal of Medical Genetics.

Coyne, J.C., Kruus, L., Kagee, A., Thopson, R., & Palmer, S.C. (in press). Benign mental health consequences of screening for mutations of *BRCA1/BRCA2*. American Journal of Medical Genetics.

Palmer, S.C., Kagee, A., Kruus, L. & Coyne, J.C. (in press). Over-emphasis of psychological risks of genetic testing may have "dire" consequences. Psychosomatics.

Kagee, A., Racioppo, M., Kruus, L., Palmer, S.C. & Coyne, J.C. (2001). Characteristics of women who choose to receive results of genetic testing for cancer risk, Annals of Behavioral Medicine, 23 (Suppl.), S068.

Palmer, S.C, Racioppo, M., Kagee, A., Thompson, R., Coyne, J.C. (2001). Marital satisfaction in the long-term physical and psychosocial adaptation of women to cancer. Annals of Behavioral Medicine, 23 (Suppl.), S079.

Ractioppo, M.W., Armstrong, K., Weber, B., & Coyne, J.C. (2001). Comparison of numeric, qualitative, and comparitive measures of breast cancer risk perception. Unpublished manuscript.

Coyne, J.C., Thompson, R., & Racioppo, M.W. (2000). Validity and efficiency of screening for history of depression by self-report.Psychological Assessment, 13(2), 163-170.

Coyne, J.C., Benazon, N.R., Gaba, C.G., Calzone, K., & Weber, B.L. (2000). Distress and psychiatric morbidity among women from high-risk breast and ovarian cancer families. Journal of Consulting and Clinical Psychology, 68(5), 864-874.

Coyne, J.C., & Anderson, K. K. (1999). Marital status, marital satisfaction, and support processes among women at high risk for breast cancer. Journal of Family Psychology, 13, 629-641.

The following are professional presentations based on data from the current study:

Kruus, L.K., Racioppo, M.W., & Coyne, J.C. (2001). Distress in anticipation of BRCA1/2 Testing: Some relevant comparisons. To be presented at the American Psychological Association's Enhancing Outcomes in Women's Health: An Interdisciplinary Conference, October.

Racioppo, M.W., & Coyne, J.C. (2001). Husbands of women anticipating genetic testing for risk of breast cancer. To be presented at the American Psychological Association's Enhancing Outcomes in Women's Health: An Interdisciplinary Conference, October.

Kagee, A., Racioppo, M., Kruus, L., Palmer, S., & Coyne, J. (2001). Characteristics of women who choose to receive results of genetic testing for cancer risk. Presented at the Society of Behavioral Medicine, Seattle, WA, March.

Racioppo, M. W., Armstrong, K. A., Kruus, L. K., & Coyne, J. C. (2000). Understanding risk perception among women attending the Cancer Risk Evaluation Program. Poster presented at the Eunice and Irving Leopold Annual Scientific Symposium and Retreat, Philadelphia, PA, March.

Kruus, L.K., Racioppo, M.W., & Coyne, J.C. (2000). Distress in anticipation of BRCA1/2 testing: Some relevant comparisons.Poster presented at the Eunice and Irving Leopold Annual Scientific Symposium and Retreat, Philadelphia, PA, March.

CONCLUSIONS

This study has contributed several valuable conclusions to the understanding of genetic testing for cancer risk. One important conclusion is that, at least among this group of self-selected women, reports of extreme psychological distress and, especially, psychiatric diagnoses, were rare. At their baseline assessment prior to being offered genetic testing, both women affected and unaffected by breast cancer were remarkably free of psychological distress and psychiatric morbidity. Despite their increased risk for breast and ovarian cancers, as well as their repeated exposure to breast cancer personally or through their relatives, they appeared resilient in the face of the potentially stressful experience of genetic testing. Our findings have a number of implications. Most importantly, it appears that when women approach the process of counseling, education, and decision making about testing, they will not be impaired by their pre-existing psychological state. That is not to say that the actual experience of counseling, having to make a decision about testing, or the receipt of positive results will not engender distress. However, the assumption that these women will approach the process of genetic testing with distress and psychiatric morbidity was not substantiated by our findings. Rather, the results suggest that any substantial elevations of distress and psychiatric morbidity following the counseling process are best attributed to that process and not to the preexisting state of the women. It follows that efforts to manage psychological distress and the education and consent process should focus on acute needs, rather than be based on the assumption of chronic psychological problems.

Further, preliminary analyses of responses of women who have completed assessments through 12-month follow-ups suggest this pattern of resiliency and little distress persists over time. Looking at changes in psychological distress through the course of the genetic testing process, it appears that there may be a slight increase in reported distress during the few months after receiving test results, but that this increase does not reach clinical levels of symptomatology, and resolves to levels below those reported by women at baseline assessment. These same patterns were found for cancer-specific worry, and for interference in daily functioning due to cancer worry.

These distress findings have a number of implications that go beyond the question of determining the psychological state of women seeking predictive testing for risk of breast cancer. We have demonstrated that long-term survivors of cancer can be relatively free of psychological distress and psychiatric morbidity. Even though over half our sample were survivors of breast cancer, and had a greater lifetime incidence of depression than the unaffected women, these women were well within the expected prevalence for a representative sample of community-residing women. The low levels of distress and morbidity reported in this study suggest that previous findings of elevated distress may be confined to early adjustment to a diagnosis of cancer, or to the advanced stages of the disease. Our findings add to accumulating evidence than cancer does not necessarily result in psychiatric morbidity. We believe that

attention can be more productively directed at better understanding why these women defy the not unreasonable assumption that they are a distressed, depressed, and anxious group. The experience of living with familial risk of cancer may well have had a resiliency-building effect that more than cancels any vulnerability associated with it. The particular aspects of this experience, that cultivates resiliency and vulnerability, need to be specified. As others have noted, adversity can produce resiliency as well as vulnerability, and women anticipating testing provide an excellent opportunity to study this (e.g., Schaeffer & Moos, 1992).

An alternative explanation for the relative lack of distress reported by women in this sample is that the cancer registry draws a highly selective group of women. We certainly found that our sample is unusually stable - psychologically, financially, and maritally. We remain concerned about the generalizability of our findings, and those of other investigations of high-risk women drawn from registry samples. Members of high-risk families jointly participate in these registries, and they typically have marshaled considerable social support to manage their shared sense of being at high risk for cancer. Participation in these registries has also given these women exceptional opportunities to become informed about their risk of cancer and genetic testing, to come to terms with their risk status, and to evaluate the advantages and disadvantages of testing for themselves and their families.

In contrast, women from the community seeking testing are likely to be less socially advantaged, and less informed about, or are psychologically ill-prepared for, the dilemma of whether to proceed with testing. For these women, the decision to pursue testing may be precipitous and tied to recent stressors, such as positive mammography findings, or the diagnosis or death of a family member. Pre-existing psychological distress may impair these women's efforts to become educated about, and to decide on, the merits of testing for them. They may be naive about the potentially negative insurance issues and social discrimination associated with being known to have an altered gene. Social support related to being at high risk and to deciding about testing may be deficient or absent. Without appropriate services these women may obtain testing without giving adequate informed consent, which may have negative psychosocial consequences rather than the intended benefits of testing. Yet, at the present time, we lack the knowledge needed to specify just what services are appropriate. To address this lack of knowledge, we have begun studying women seeking assistance in evaluating and managing their cancer risk through the Cancer Risk Evaluation Program at the University of Pennsylvania Cancer Center. The intent of this work is to identify selection biases and discrepancies in experiences of registry and community women, data that will have direct and immediate application in the refining and evaluating of urgently needed clinical protocols.

Another important conclusion from this study relates to the psychometrics of assessing important constructs such as psychological distress and risk perception. Our analyses found that self-reports of history of depression are greatly influenced by present mood, suggesting that researchers should not rely solely on such screening questions to assess depression history. Also, our psychometric and qualitative studies of risk perception among high-risk women suggests that there may be a disconnect between how

researchers and participants view risk. Both findings have implications for assessing and predicting response to genetic testing, and for how providers might intervene, or decide not to intervene.

In addition to clarifying distress and characteristics unique to our sample, we also uncovered interesting differences between women with a personal history of cancer, and those without, in terms of perceived risk of breast cancer, and motivation and intention to seek testing. For instance, women with a personal history of breast cancer perceived their short-term and lifetime risks of breast cancer as significantly lower than women without a personal history. Further analyses will explore possible explanations for this finding, including the degree to which it can be explained by a sense that one cancer event may protect against future events, that affected women perhaps feel more confident in their screening plan, or that past treatments, such as mastectomy, confer a lower sense of risk. Also, affected women were significantly more likely than other women to report they intend to seek testing immediately after it becomes available, and to pursue testing in order to clarify their children's risk of cancer.

Also regarding women's perceptions of breast cancer risk, all women overestimated their lifetime risk of breast cancer relative to objective risk estimates. It may be that psychosocial factors such as salient experiences with family members affected by cancer, or frequent focus on cancer and health may influence risk perception beyond objective information. Interestingly, women with and without a personal history of cancer reported different levels of risk perception at baseline, and different patterns of change from baseline to post-results follow-up. At baseline, affected women reported significantly lower risk perception than did unaffected women. However, at follow-up, affected women reported significantly higher risk perception than did unaffected women.

Another interesting finding relates to how women with and without a personal history of cancer make meaning out of their experiences with genetic testing. Specifically, unaffected women reported higher levels of post-traumatic growth regarding testing than did affected women. One possible explanation is that the experience of cancer re-calibrates a woman's sense of the meaning of stress, so that genetic testing becomes less of a traumatic event when one has already had cancer. These results corroborate the findings that affected and unaffected women experience genetic testing differently, and suggest that the needs of women regarding genetic testing may depend upon their personal cancer history.

This study has given us the opportunity to describe the process of genetic testing for cancer risk among a large sample, and in collaboration with clinical staff. We have collected a rich database of information about the process of testing, being offered results, and moving through to short-term follow-up. While we have already been able to publish and present some of this data, we have only just begun to realize the full potential of the data collected. We plan to continue to bring this data to bear in answering questions about the process of genetic testing, and to disseminate the findings so that we might ultimately improve the quality of patient care among people managing cancer risk.

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APPENDIX

APPENDIX

A. PRINCIPAL INVESTIGATOR'S CV
B. MEASURES
C. PUBLICATIONS
D. PERSONNEL LIST FOR DAMD17-96-1-6157

APPENDIX A: PRINCIPAL INVESTIGATOR'S CV

UNIVERSITY OF PENNSYLVANIA - SCHOOL OF MEDICINE
Curriculum Vitae

Date: July 2001

James C. Coyne, Ph.D.

Office Address: 11 Gates Building
3400 Spruce Street
Philadelphia, PA 19104-4283

Education: 1964-69 B.S. Carnegie-Mellon University (Psychology)
1969-76 Ph.D. University of Indiana

Postgraduate Training and Fellowship Appointments:

1972-73 Intern in Psychology, Division of Clinical Psychology, J. Hillis Miller Medical Center, University of Florida, Gainesville

1984-85 Research Fellowship, Institute for Social Research, University of Michigan, Ann Arbor

Military Service: None

Faculty Appointments:

1998-present Professor, Department of Psychiatry, University of Pennsylvania School of Medicine

1998-present Professor, Department of Family Practice and Community Medicine

1999-present Senior Fellow, Leonard Davis Institute of Health Economics

1998-present Adjunct Professor, Departments of Family Practice and Psychiatry, University of Michigan Medical School, Ann Arbor

1992-1998 Professor, Departments of Family Practice and Psychiatry, University of Michigan Medical School, Ann Arbor

1986-1992 Associate Professor, Departments of Family Practice and Psychiatry, University of Michigan Medical School, Ann Arbor

1985-1986 Lecturer, Department of Family Practice, University of Michigan, Ann Arbor

1985-1998	Faculty Associate, Institute for Social Research, University of Michigan, Ann Arbor
1976-1984	Assistant Professor, Department of Psychology, University of California, Berkeley
1975-1976	Assistant Professor, Department of Psychology, Miami University, Oxford, OH
1973-1975	Instructor, Department of Psychology, Miami University, Oxford, OH

Hospital and Administrative Appointments:

1998-present	Co-Director, Health Services and Behavioral Sciences Program, University of Pennsylvania Cancer Center
1992-1998	Director of Psychosocial Research Depression Program, Department of Psychiatry, University of Michigan Medical School
1982-1984	Co-Director, Mood Disorders Center, Mental Research Institute, Palo Alto, CA
1979-1984	Director of Research, Mental Research Institute, Palo Alto, CA

Specialty Certification: None

Licensure: Licensed Psychologist, State of Michigan
Licensed Psychologist, Commonwealth of Pennsylvania

Awards, Honors and Membership in Honorary Societies:

1965-1969	Carnegie Fund Scholarship
1969-1972	USPHS Fellow in Clinical Psychology
1975	Miami University Summer Fellowship for Innovation in Teaching
1977	Psi Chi Psychology Professor of the Year
1977	Don D. Jackson Memorial Award
1978	University of California Career Development Award
1979	Don D. Jackson Memorial Award
1992	Ranked 21st of all psychologists in impact, 1986-1990, by Current Contents: Social and Behavioral Sciences
1994	Listed among 327 Best Mental Health Experts, Good House-keeping Magazine
1994	Award for Outstanding Scholarship in the Field of Marriage and Family Therapy, Michigan Association for Marriage and Family Therapy

1995	Sixth Most-Cited Article in Psychology of the Nineties (Downey and Coyne, 1990), Current Contents, Social and Behavioral Sciences
1995	Elected Fellow, Division 43, American Psychological Association
1996	Honorable Mention, Best Research Paper in Family Medicine Award, Society of Teachers of Family Medicine and Ross Laboratories
2000	American Psychological Association: 1999 Presidential Award for Contributions to Family Psychology and Health
2000	Elected to the Academy of Behavioral Medicine Research

Memberships in Professional and Scientific Societies:

National Societies:

Fellow, American Psychological Association
Society for Study of Clinical Psychology as a Science
Academy of Behavioral Medicine Research
Society of Behavioral Medicine
Association for Advancement of Behavior Therapy

International:

International Society for Research on Emotion

Local Societies: None

National Scientific Committees:

Data and Safety Monitoring Board, ENRICH-D Study, NHLBI, 1997-present

Local Scientific Committees: None

Editorial Positions:

2000-present	Health Psychology
1998-present	Consulting Editor, Journal of Personality and Social Psychology
1997-present	Annals of Behavioral Medicine
1992-present	Editorial Board, Journal of Psychotherapy Integration
1986-present	Consulting Editor, Journal of Family Psychology
1986-present	Consulting Editor, Journal of Systemic and Strategic Therapies
1979-present	Consulting Editor, Journal of Marital and Family Therapy
1986-1993	Consulting Editor, Journal of Personality and Social Psychology
1990-1993	Consulting Editor, Topics in Family Psychology and Counseling
1986-1991	Editorial Board, Family Process
1979-1989	Consulting Editor, Journal of Abnormal Psychology
1983-1988	Advisory Board, Clinical Research Digest

1983-1986	Associate Editor, <u>Journal of Social and Personal Relationships</u>
1981-1984	Associate Editor, <u>American Family Therapy Association Newsletter</u>
1980-1986	Consulting Editor, <u>Cognitive Therapy and Research</u>

<u>Academic Committees at the University of Michigan and Affiliated Hospitals</u>:

Department of Family Medicine:

1993-1996   Member, Promotion and Tenure Committee
1989-1998   Member, Research Committee

Department of Psychiatry:

1988-1993   Member, Research Committee
1993-1998   Member, Psychology Training Committee
1993-1998   Reviewer, Psychiatry Intramural Grant Program

<u>Major Teaching and Clinical Responsibilities at the University of Michigan and Affiliated Hospitals</u>:

Department of Family Medicine:

1992-1996   Supervisor, Undergraduate Research Opportunity Program
1992-1996   Supervisor and Principal Investigator, Minority Research Opportunities
1994-1998   Director, Junior Faculty Research Mentorship Program

Department of Psychiatry:

1986-1994   Supervisor, Psychology Internship Program
1987-1998   Director of Psychosocial Research, Depression Program
1993-1998   Supervisor, Psychology Postdoctoral Fellowship Program
1996-1998   Faculty, Interpersonal Psychotherapy Workshops
1996-1998   Faculty, Brief Therapy Resident Mentorship
1992-1998   Member, Cancer Center

<u>Major Teaching and Clinical Responsibilities at the University of Pennsylvania and Affiliated Hospitals</u>:

1998-present Member, Clinical Trials Committee, University of Pennsylvania
                        Comprehensive Cancer Center
1999-present Member, Office of Health Services Advisory Board

Lectures by Invitation:

1994	"Marital relationship and predictive testing for early-onset breast cancer." Annual Meeting of the American Psychological Association, Los Angeles.
1995	"Talking to people who don't want to talk to us: Practical approaches to mandatory services." Integrated Children's Services Conference, Toronto
1995	"Personality as a diathesis for depression: a limited and limiting perspective." World Congress of Behavioral and Cognitive Therapies, Copenhagen
1995	"Depression in primary care versus psychiatric settings." Annual Meeting of the American Psychological Association, New York
1995	"Physician detection of depression does not improve outcome." Annual Meeting of the American Psychological Association, New York
1995	"Cardiology: rediscovering the family context of heart problems." Presidential Miniconvention Symposium, Annual Meeting of the American Psychological Association, New York
1995	"Challenging the medicalization of discontent: research opportunities." Presidential Miniconvention Symposium, Annual Meeting of the American Psychological Association, New York
1995	"Marital style and coping with congestive heart failure." Annual Meeting of the American Psychological Association
1995	"Spouses of women seeking predictive testing for breast cancer." Annual Meeting of the American Psychological Association, New York
1995	"Collaboration and independence in couples confronting congestive heart failure." Annual Meeting of the American Psychological Association, New York
1995	"Depression in primary care." Department of Psychiatry Grand Rounds, Henry Ford Hospital, Detroit
1996	"The future is now: genetic testing for risk of breast cancer." Midwestern Psychological Association, Chicago
1996	"Major depression and distress: effects on self-concept and coping." Annual Meeting of the American Psychological Association, Toronto
1996	"Distress and burden among the husbands and wives of depressed persons." Annual Meeting of the American Psychological Association, Toronto
1996	"Marital distress and coping tactics of depressed women and their husbands." American Psychological Association, Toronto

1997	"Depression in primary care: psychology's new frontier?" Southeastern Psychological Association, Atlanta
1997	"Brief psychotherapy for depression." Institut Gregory Bateson, Paris
1997	"Intervening with individuals, couples, and families: l'ecole de Palo Alto." Institut Gregory Bateson, Liege, Belgium
1997	"Categories and continua: social filters, distress, and depression." Annual Meeting of the American Psychological Association, Chicago
1997	"Life events, distress, and depression in primary care and psychiatric patients." Annual Meeting of the American Psychological Association, Chicago
1997	"Contextual approach to the assessment of coping." Annual Meeting of the American Psychological Association, Chicago
1997	Relationship-focused coping among congestive heart failure patients and their spouses." Annual Meeting of the American Psychological Association, Chicago
1997	"Improving coping research: raze the slum before any more building." Annual Meeting of the American Psychological Association, Chicago

Presentations:

Coyne, J.C., Brown, G., Katz, I.R., Schulberg, H.C., & Brown, E. A chronic disease model for the management of depression in the primary care elderly. Presented at the annual meeting of the American Psychiatric Association, Chicago, IL, May 2000.

Datto, C., Coyne, J., Miani, M., Horowitz, D., Katz, I.R. Initial experience with a primary care depression disease management program. Presented at the Young Investigators' Poster Session, annual meeting of the American Psychiatric Association, Chicago, IL, May 2000.

Harralson, T., Brody, P., Coyne, J., Regenberg, A., Katz, I., Thompson, R., & Hadley, T. Depression and general medical comorbidity in a behavioral health managed care setting. Presented at the annual meeting of the American Psychiatric Association, Chicago, IL, May 2000.

Thompson, R., Harralson, T. Regenberg, A., Purnell, T., Katz, I., Coyne, J., & Hadley, T. The effects of perceived health on psychiatric outcomes. Presented at the annual meeting of the American Psychiatric Association, Chicago, IL, May 2000.

Racioppo, M.W., Coyne, J.C., & Palmer, S.C. <u>Husbands of women anticipating</u>
<u>genetic testing for risk of breast cancer</u>. Paper presented at the American
Psychological Association's Women's Health Outcomes Conference,
Washington, D.C, October 2000.

Streim, J.E., Gallo, J.J., Coyne, J., Katz, I.R. <u>Antidepressant drug use in older</u>
<u>adult primary care patients with depression</u>. Presented at the Annual
Meeting of the Gerontological Society of America, November 2000.

Coyne, J.C., Thompson, R., & Gallo, J.J. <u>Relapse prevention in primary care:</u>
<u>Some flies in the ointment</u>. Paper presented at NIMH conference, State of
the Science of Relapse Prevention in Major Depression, Potomac, MD,
May 2001.

<u>Organizing Roles in Scientific Meetings:</u> None

<u>Bibliography:</u>

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<u>Psychology, 85</u>, 186-193 (1976).

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Patents: None

APPENDIX B: MEASURES

I.   Baseline Questionnaires
II.   Proband Interim Questionnaires
III. Pre-Results Questionnaires
IV.   Supplemental Questionnaires
V.   Post-Results Questionnaires/Interview
VI.   Long-Term Follow-Up Questionnaire
VII. Spouse/Sibling Questionanres
VIII. Telephone Contact Sheet

B.I. Baseline Questionnaires
Proband Baseline Questionnaire (Affected & Unaffected)
Proband Baseline Telephone Interview

☐☐☐☐ - ☐

WOMEN'S HEALTH STUDY
Baseline Questionnaire

Version A

Version A0-August 1997

Today's Date _____   **ID-A**_____

Background Data

A1.   Date of Birth   _____Month _____Day _____Year

A2.   Ethnic Background: White   ☐   Black   ☐
                                    Hispanic   ☐   Asian   ☐
                                    Native American   ☐   Other   ☐

A3.   Religion: Catholic   ☐   Protestant   ☐
                          Jewish   ☐   Other   ☐
                          None   ☐

A4.   Are you currently (**please check one**)?
☐   Single   ☐ Married
☐   Not married, but living in a steady,   ☐ Separated
      marriage-like relationship   ☐ Divorced   ☐   Widowed

A5a.   If you **are** currently married, what was the date of your current marriage?
           Month _____   Year _____

A5b.   Is this your first marriage?   Yes   ☐   No   ☐

A6.   How many children do you have? _____

          A6a1. Ages of **DAUGHTERS**:   a. _____   b. _____   c. _____
                                                d. _____   e. _____   f. _____

          A6a2. Ages of **SONS**:   a. _____   b. _____   c. _____
                                           d. _____   e. _____   f. _____

          A6a.   Number of children living at home   _____
          A6b.   Number who are under age 6   _____

A7.   Are you currently working for pay outside the home? Yes ☐No ☐

A8.   If **yes**, about how many hours per week are you working for pay?
          Less than 10   10-20   21-30   31-40   41 or more
               ☐   ☐   ☐   ☐   ☐

A9.   What is the highest level of education you have completed? (**Check one**)
          ☐   Less than 9th grade   ☐   Dropped out of high school
          ☐   Completed high school   ☐   Some college
          ☐   Completed college   ☐   Some graduate or professional
          ☐   Completed graduate or professional   training
       training

The following two questions are optional, but we hope that you will provide this information. Please
check the appropriate box. (**Check one**)

A10. What is your household's total income? (**Check one**)
☐   Less than $10,000   ☐ $10,000 to $19,999   ☐ $20,000 to $29,999

☐ $30,000 to $39,999   ☐ $40,000 to $49,999   ☐ $50,000 to $59,999
☐ $60,000 to $69,999   ☐ Greater than $69,999

A11. How many people (adults and children) does this income support? _____

B1. When were you first diagnosed with breast cancer? Month _____ Year_____
B2. Have your lymph nodes been affected?

   Yes ☐   No ☐   Do Not Know ☐

B3. Do you currently consider yourself in remission?

   Yes ☐   No ☐   Do Not Know ☐

B4. What treatment(s) have you received for breast cancer?

   Chemotherapy   Yes ☐   No ☐
   Radiation   Yes ☐   No ☐
   Surgery   Yes ☐   No ☐

B5. Have you ever been diagnosed with ovarian cancer? Yes ☐   No ☐
   If **yes**, when? Month _____ Year_____

B6. Have you ever had any of the following surgical procedures? (**Please check all that apply**).

   B6a. _____Lumpectomy (Removal of lump from breast)

      If yes, when?   Month _____ Year_____

   B6b. _____Oophorectomy (Removal of ovaries)

      If yes, when? Month _____ Year_____

   B6c. _____Unilateral mastectomy (Removal of one breast)

      If yes, when? Month _____ Year_____

   B6d._____Hysterectomy (Removal of uterus)

      If yes, when? Month _____ Year_____

   B6e. _____Bilateral mastectomy (Removal of both breasts)

      If yes, when? Month _____ Year_____

B7. Before your diagnosis of breast cancer, how likely did you think you were to develop breast cancer, compared to the average woman? (**Please circle one**)

   Much Less Likely   Much More Likely
      1   2   3   4   5

B8. Before your diagnosis of breast cancer, how likely did you think you were to develop breast cancer, compared to other women in your family? (**Please circle one**)

   Much Less Likely   Much More Likely
      1   2   3   4   5

B9. Overall, what do you believe your risk is of developing breast cancer *again* **in the near future**?

   0%   10%   20%   30%   40%   50%   60%   70%   80%   90%   100%

B10. Overall, what do you believe your risk is of developing breast cancer *again* **at some point in your lifetime**?

   0%   10%   20%   30%   40%   50%   60%   70%   80%   90%   100%

B11. Overall, what do you believe your risk is of developing a metasis (cancer spreading to another site) **in the near future?**

0%   10%   20%   30%   40%   50%   60%   70%   80%   90%   100%

B12. Overall, what do you believe your risk is of developing a metasis **at some point in your lifetime?**   0%   10%   20%   30%   40%   50%   60%   70%   80%   90% 100%

B13. Overall, what do you believe your risk is of developing cancer **unrelated** to your breast   cancer **in the near future?**

0%   10%   20%   30%   40%   50%   60%   70%   80%   90%   100%

B14. Overall, what do you believe your risk is of developing cancer **unrelated** to your breast   cancer **at some point in your lifetime?**

0%   10%   20%   30%   40%   50%   60%   70%   80%   90%   100%

B15. A medical test may soon be available that allows some women to learn their genetic risk for developing a form of breast and ovarian cancer that runs in families. Even though   you have been diagnosed with breast cancer, would you consider taking the genetic test to   learn if your cancer is the type that runs in families? **(Please check one response).**

_____   I will <u>definitely</u> take the test immediately when it becomes available.

_____   I will <u>definitely</u> take the test, but I am not sure if immediately.

_____   I will <u>probably</u> take the test immediately when it becomes available.

_____   I will <u>probably</u> take the test, but not immediately.

_____   I am <u>undecided</u> whether I will take the test.

_____   I will <u>probably not</u> take the test.

_____   I will <u>definitely not</u> take the test.

B16. If you think you will probably or definitely take the test, what are your reasons for doing so? **(Please check all that apply; some may not apply to you).**

_____   To plan for the future.

_____   To reduce the uncertainty.

_____   To know I have to be more careful about doing self examinations and getting regular checkups.

_____   To make decisions about whether to get preventive surgery.

_____   To make decisions about family planning.

_____   To find out the risk that may be transmitted to my children.

_____   Family members want me to get testing.

_____   Other (describe) _____

B17. If you **do not** think you will probably or definitely take the test, what are your reasons for **not** doing so? **(Please check all that apply; some may not apply to you).**

_____   I am happier not knowing.

_____   It would be too upsetting to learn that I am at high risk for breast cancer.

_____   I believe I already know what my risk for breast cancer is.

_____   There would not be much I could do if I found out I was at high risk for breast cancer.

4

_____ I do not feel able emotionally to deal with testing.

_____ Family members do not want me to get testing.

_____ Risk to my insurance coverage.

SECTION C

For the next questions we are interested in how people close to you respond to you when you are in need of support or reassurance. In answering the questions in the **first column**, please keep in mind a female family member who may be at risk for breast cancer **with whom you are closest**. Answer the questions in the **second column** keeping in mind **your spouse or intimate partner**. *If you do not have a spouse or intimate partner, please leave the second column blank.* For the **third column**, please keep in mind **another family member or friend to whom you are closest**.

	Female Family Member at Risk for Breast Cancer	Spouse/Partner	Another Family Member/ Friend
C1. Was physically present when you needed them.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
C2. Told you what he/she did in a similar situation.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
C3. Did activities to help you get your mind off things.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
C4. Told you that the things you talk about are private--just between the two of you.	☐ Yes ☐ No ☐	Yes ☐ No	☐ Yes ☐ No
C5. Suggested some action you should take.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
C6. Comforted you by showing you physical affection.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
C7. Listened to you talk about your private feelings.	☐ Yes ☐ No ☐	Yes ☐ No	☐ Yes ☐ No
C8. Agreed that what you want to do is right.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
C9. Told you how he/she felt in a similar situation.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
C10. Let you know that he/she will always be around if you need assistance.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
C11. Gave you feedback on how you were doing without saying it was good or bad.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
C12. Pitched in and helped you do things that needed to get done.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
C13. Intruded into your personal feelings and concerns.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No

	Female Family Member at Risk for Breast Cancer	Spouse/Partner	Another Family Member/ Friend
C14. Gave you unsolicited advice.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
C15. Attempted to make unwanted contact.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
C16. Discouraged you from discussing your feelings and concerns.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
C17. Minimized your worries or concerns.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
C18. Rejected you for displaying emotional upset.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
C19. Insisted that you remain upbeat and optimistic.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
C20. Let you down when you were counting on him/her.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No

C21. Is there anyone in your life with whom you can share your most private feelings without holding back?

☐ Yes ☐ No

C21a. **If you are married or living with a partner**, can you share your most private feelings with this partner without holding back?

☐ Yes ☐ No

SECTION D

D1. Have any of the events listed happened to you in the past six months? **(Check All That Apply)**

a. ☐ You retired or were fired or laid off from work.-

b. ☐ You were unemployed and looking for work.

c. ☐ Your spouse retired or was fired or laid off from work.

d ☐ Your spouse was unemployed and looking for work.

e. ☐ You had problems with the police or court.

f. ☐ You got into serious financial difficulties.

g. ☐ A close family member was seriously ill or injured.

h. ☐ You had a marital separation or divorce.

i. ☐ You had serious troubles with relatives or close friends.

j. ☐ Your spouse had troubles difficulties with relatives or close friends.

k. ☐ A close family member died.

l. ☐ A close friend or relative died.

m. ☐ You were seriously ill or injured.

SECTION E

For each of these statements, please indicate the extent to which you agree or disagree by circling the appropriate number. Try to be as accurate and as honest as you can, and try not to let your answer to one question influence your answers to other questions. There are no right or wrong answers. We are only interested in your opinions.

		Strongly Disagree		Neutral		Strongly Agree
E1.	In uncertain times, I usually expect the best.	1	2	3	4	5
E2.	It's easy for me to relax.	1	2	3	4	5
E3.	If something can go wrong for me, it will.	1	2	3	4	5
E4.	I always look on the bright side of things.	1	2	3	4	5
E5.	I'm always optimistic about my future.	1	2	3	4	5
E6.	I enjoy my friends a lot.	1	2	3	4	5
E7.	It's important for me to keep busy.	1	2	3	4	5
E8.	I hardly ever expect things to go my way.	1	2	3	4	5
E9.	Things never work out the way I want them to	1	2	3	4	5
E10.	I don't get upset too easily.	1	2	3	4	5
E11.	I'm a believer in the idea that "every cloud has a silver lining".	1	2	3	4	5
E12.	I rarely count on good things happening to me.	1	2	3	4	5

PLEASE CONTINUE ON TO NEXT PAGE
SECTION F

Below is a list of words which people might use to describe themselves. You are asked to rate them **twice**. First, please indicate for each word *how well it describes you* and second, *how much it matters to you* using the following scale.

1	2	3	4	5
Extremely	Very much	Somewhat	Not very well	Not at all

		DESCRIBES ME					MATTERS TO ME				
F1.	Involved in family	1	2	3	4	5	1	2	3	4	5
F2.	Aware of being a woman	1	2	3	4	5	1	2	3	4	5
F3.	Involved in paid work	1	2	3	4	5	1	2	3	4	5
F4.	Being a mother	1	2	3	4	5	1	2	3	4	5
F5	Involved in organization/ volunteer work	1	2	3	4	5	1	2	3	4	5
F6.	Being a grandmother	1	2	3	4	5	1	2	3	4	5
F7.	Physically attractive	1	2	3	4	5	1	2	3	4	5
F8.	Being a wife	1	2	3	4	5	1	2	3	4	5
F9.	Healthy	1	2	3	4	5	1	2	3	4	5
F10.	Being a daughter	1	2	3	4	5	1	2	3	4	5
F11.	Intelligent	1	2	3	4	5	1	2	3	4	5
F12.	Able to cope	1	2	3	4	5	1	2	3	4	5
F13.	Spiritual or religious	1	2	3	4	5	1	2	3	4	5
F14.	Outgoing	1	2	3	4	5	1	2	3	4	5
F15.	Independent	1	2	3	4	5	1	2	3	4	5
F16.	Realistic	1	2	3	4	5	1	2	3	4	5
F17.	Active	1	2	3	4	5	1	2	3	4	5
F18.	Loved	1	2	3	4	5	1	2	3	4	5
F19.	Caring	1	2	3	4	5	1	2	3	4	5

F20.	Depressed	1	2	3	4	5	1	2	3	4	5

SECTION G

In the next table, we would like you to first rate how well you think each word will describe you *in the future.* and then, indicate how important it is for you to see yourself this way *in the future*.

1	2	3	4	5
Extremely	Very much	Somewhat	Not very well	Not at all

		WILL DESCRIBE YOU					IMPORTANT FOR YOU TO SEE YOURSELF THIS WAY IN FUTURE				
G1.	Involved in family	1	2	3	4	5	1	2	3	4	5
G2.	Aware of being a woman	1	2	3	4	5	1	2	3	4	5
G3.	Involved in paid work	1	2	3	4	5	1	2	3	4	5
G4.	Being a mother	1	2	3	4	5	1	2	3	4	5
G5.	Involved in organization/volunteer work	1	2	3	4	5	1	2	3	4	5
G6.	Being a grandmother	1	2	3	4	5	1	2	3	4	5
G7.	Physically attractive	1	2	3	4	5	1	2	3	4	5
G8.	Being a wife	1	2	3	4	5	1	2	3	4	5
G9.	Healthy	1	2	3	4	5	1	2	3	4	5
G10.	Being a daughter	1	2	3	4	5	1	2	3	4	5
G11.	Intelligent	1	2	3	4	5	1	2	3	4	5
G12.	Able to cope	1	2	3	4	5	1	2	3	4	5
G13.	Spiritual or religious	1	2	3	4	5	1	2	3	4	5
G14.	Outgoing	1	2	3	4	5	1	2	3	4	5
G15.	Independent	1	2	3	4	5	1	2	3	4	5
G16.	Realistic	1	2	3	4	5	1	2	3	4	5
G17.	Active	1	2	3	4	5	1	2	3	4	5
G18.	Loved	1	2	3	4	5	1	2	3	4	5
G19.	Caring	1	2	3	4	5	1	2	3	4	5
G20.	Depressed	1	2	3	4	5	1	2	3	4	5

SECTION H

The following questions apply to persons who are <u>married or living with a partner.</u> Please complete them if you are. <u>If you are not married or living with a partner, please skip to Section I on page 13.</u>

Most persons have disagreements in their relationships. Please indicate, with check marks, on the following list, the extent of agreement or disagreement experienced between you and your partner **DURING THE PAST MONTH**.

		Always Agree	Almost Always Agree	Occa-sionally Disagree	Fre-quently Disagree	Almost Always Disagree	Always Disagree
H1.	Handling family finances						
H2.	Matters of recreation						
H3.	Religious matters						
H4.	Demonstration of affection						
H5.	Friends						
H6.	Sex relations						
H7.	Conventionality (correct or proper behavior						
H8.	Philosophy of life						
H9.	Ways of dealing with parents or in-laws						
H10.	Aims, goals, and things believed important						
H11.	Amount of time spent together						
H12.	Making major decisions						
H13.	Household tasks						
H14.	Leisure time interests and activities						
H15.	Career decisions						

		All of the time	Most of the time	More often than most	Occa-sionally	Rarely	Never
H16.	How often do you discuss or have you considered divorce, separation, or terminating your relationship?						
H17.	How often do you or your mate leave the house after a fight?						
H18.	In general, how often do you think that things between your and your partner are going well?						
H19.	Do you confide in your mate?						
H20.	Do you ever regret that you married (or lived together)?						
H21.	How often do you and your partner quarrel?						
H22.	How often do you and your mate "get on each other's nerves?"						

		Every Day	Almost Every Day	Occa-sionally	Rarely	Never
H23.	Do you kiss your mate?					

		All of Them	Most of Them	Some of Them	Very few of Them	None of Them
H24.	Do you and your mate engage in outside interests together?					

How often would you say the following events occur between you and your mate?

		Never	Less than once a month	About twice a month	About twice a week	Once a day	More Often
H25.	Have a stimulating exchange of ideas.						
H26.	Laugh together.						
H27.	Calmly discuss something.						
H28.	Work together on a project.						

These are some things couples sometimes agree and sometimes disagree upon. Indicate if either item below caused differences of opinions or were problems in your relationship during the past month. **(Check yes or no)**.

H29.   Being too tired for sex.   ☐ Yes   ☐ No

H30.   Not showing love.   ☐ Yes   ☐ No

H31.   The following scale represents different degrees of happiness in your relationship. The middle point "happy" represents the degree of happiness of most relationships. Please circle the statement which best describes the degree of happiness, all things considered, of your relationship.

Extremely Unhappy	Fairly Unhappy	A Little Unhappy	Happy	Very Happy	Extremely Happy	Perfect

H32.   Please check one of the following statements which best describes how you feel about the **future** of your relationship.

_____   I want desperately for my relationship to succeed, and would go to almost any length to see that it does.

_____   I want very much for my relationship to succeed, and will do all I can to see that it does.

_____   I want very much for my relationship to succeed, and will do my fair share to see that it does.

_____   It would be very nice if my relationship succeeded, but I can't do much more than I am doing now to help it succeed.

_____   It would be nice if it succeeded, but I refuse to do any more than I am doing now to keep the relationship going.

_____   My relationship can never succeed, and there is no more that I can do to keep the relationship going.

PLEASE CONTINUE ON TO NEXT PAGE

SECTION I

I1.   In general, would you say your health is:

☐ Excellent   ☐ Very Good   ☐ Good   ☐ Fair   ☐ Poor

I2.   Compared to one year ago, how would you rate your health in general now?(**Check one**)

☐ Much better now than one year ago
☐ Somewhat better now than one year ago
☐ About the same as one year ago
☐ Somewhat worse now than one year ago
☐ Much worse than one year ago

I3.   The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much? *Please mark the appropriate box to indicate your response.*

		YES, limited a lot.	YES, limited a little.	NO, not limited at all.
a.	Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports.			
b.	Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf.			
c.	Lifting or carrying groceries.			
d.	Climbing several flights of stairs.			
e.	Climbing one flight of stairs.			
f.	Bending, kneeling, or stooping.			
g.	Walking more than a mile.			
h.	Walking several blocks.			
i.	Walking one block.			
j.	Bathing or dressing yourself.			

4.   **During the past 4 weeks**, have you had any of the following problems with your work or other regular daily activities as a result of your **physical** health?

    I4a.   Cut down the amount of time you spent on work or other activities.

        ☐ Yes   ☐ No

    I4b.   Accomplished less than you would like.

        ☐ Yes   ☐ No

    I4c.   Were limited in the kind of work or other activities.

        ☐ Yes   ☐ No

    I4d.   Had difficulty performing the work or other activities (for example, it took extra effort).

        ☐ Yes   ☐ No

I5.   **During the past 4 weeks**, have you had any of the following problems with your work or other regular daily activities as a result of any **emotional** problems (such as feeling depressed or anxious)?

    I5a.   Cut down the amount of time you spent on work   ☐ Yes   ☐ No
        or other activities.

    I5b.   Accomplished less than you would like.   ☐ Yes   ☐ No

    I5c.   Didn't do work or other activities as   ☐ Yes   ☐ No
        carefully as usual.

I6.   **During the past 4 weeks**, to what extent has your physical health or emotional   problems interfered with your normal social activities with family, friends, neighbors, or   groups?

    ☐ Not at all   ☐ Slightly   ☐ Moderately   ☐ Quite a bit   ☐ Extremely

I7.   How much bodily pain have you had **during the past 4 weeks**?

    ☐ Not at all   ☐ Slightly   ☐ Moderately   ☐ Quite a bit   ☐ Extremely

I8.   **During the past 4 weeks**, how much did pain interfere with your normal work (including both work outside the home and housework)?

    ☐ Not at all   ☐ Slightly   ☐ Moderately   ☐ Quite a bit   ☐ Extremely

I9.   These questions are about how you feel and how things have been with you during the past **4 weeks**. For each question, please give the one answer that comes closest to the

way you have been feeling. How much of the time **during the past 4 weeks**: *Please mark the appropriate box to indicate your response.*

		All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
a.	Did you feel full of pep?						
b.	Have you been a very nervous person?						
c.	Have you felt so down in the dumps that nothing could cheer you up?						
d.	Have you felt calm and peaceful?						
e.	Did you have a lot of energy?						
f.	Have you felt downhearted and blue?						
g.	Have you been a happy person?						
h.	Did you feel tired?						

I10. **During the past 4 weeks**, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

☐ All of the time ☐ Most of the time ☐ A good bit of the time ☐ Some of the time ☐ A little of the time ☐ None of the time

PLEASE CONTINUE ON TO NEXT PAGE

I11. How **TRUE** or **FALSE** is each of the following statements for you?

	Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
a. I seem to get sick a little easier than other people.					
b. I am as healthy as anybody I know.					
c. I expect my health to get worse.					
d. My health is excellent.					

I12. In **the past 6 months**, have you had two weeks or more when nearly every day you felt sad, blue, or depressed <u>or</u> in which you lost all interest in things like work or hobbies or things you usually liked to do for fun?

I12a. If **yes**, there was such a two-week period, did your work or relationships suffer?

☐ Yes ☐ No

I12b. If **yes**, there was such a two-week period, did you get counseling or psychotherapy?

☐ Yes ☐ No

I12c. If there was such a two-week period, did you get medication for this condition?

☐ Yes ☐ No

I13. Are you **currently** receiving counseling or psychotherapy or medication for depression or emotional problems?

☐ Yes ☐ No

PLEASE CONTINUE ON TO NEXT PAGE
SECTION J

J1.   How often do you have a drink containing alcohol?

☐ Never   ☐ Monthly or less   ☐ Two to four times a month
☐ Two to three times a week   ☐ Four or more times a week

J2.   How many drinks containing alcohol do you have on a typical day when you are drinking?

☐ 1 or 2   ☐ 3 or 4   ☐ 5 or 6   ☐ 7 to 9   ☐ 10 or more

J3.   Have you ever felt you should cut down on your drinking?

☐ Yes ☐ No

J4.   Have people annoyed you by criticizing your drinking?

☐ Yes ☐ No

J5.   Have you ever felt bad or guilty about drinking?

☐ Yes ☐ No

J6.   Have you ever taken a drink first thing in the morning to steady your nerves or get rid of a hangover?

☐ Yes ☐ No

PLEASE CONTINUE ON TO NEXT PAGE

Listed Below Are Some Symptoms Of Strain That People Sometimes Have. *Please Read Each One Carefully And Check The Answer Which Best Reflects How Much That Symptom Has Bothered You During the **Past Three Months**.*

	Not at all	A little	Quite a bit	Extremely
K1. Suddenly scared for no reason				
K2. Feeling fearful				
K3. Faintness, dizziness, or weakness				
K4. Nervousness or shakiness inside				
K5. Heart pounding or racing				
K6. Trembling				
K7. Feeling tense or keyed up				
K8. Headaches				
K9. Spells of terror or panic				
K0. Feeling restless, can't sit still				
K11. Feeling low in energy--slowed down				
K12. Blaming yourself for things				
K13. Crying easily				
K14. Loss of sexual interest or pleasure				
K15. Poor appetite				
K16. Difficult falling asleep, staying asleep				
K17. Feeling hopeless about the future				
K18. Feeling blue				
K9. Feeling lonely				
K20. Feeling trapped or caught				
K21. Worrying too much about things				
K22. Feeling no interest in things				
K23. Thoughts of ending your life				
K24. Feeling everything is an effort				
K25. Feelings of worthlessness				

SECTION L

L1. Vividly imagine that you are afraid of the dentist and have to get some dental work done. Which of the following would you do? Check **all** of the statements that might apply to you.

   _____   I would ask the dentist exactly what he was going to do.

   _____   I would take a tranquilizer or have a drink before going.

   _____   I would try to think about pleasant memories.

   _____   I would want the dentist to tell me when I would feel pain.

   _____   I would try to sleep.

   _____   I would watch all the dentist's movements and listen for the sound of the drill.

   _____   I would watch the flow of water from my mouth to see if it contained blood.

   _____   I would do mental puzzles in my mind.

L2. Vividly imagine that you are being held hostage by a group of armed terrorists in a public building. Which of the following would you do? Check **all** of the statements that might apply to you.

   _____   I would sit by myself and have as many daydreams and fantasies as I could.

   _____   I would stay alert and try to keep myself from falling asleep.

   _____   I would exchange life stories with the other hostages.

   _____   If there was a radio present, I would stay near it and listen to the bulletins about what the police were doing.

   _____   I would watch every movement of my captors and keep an eye on their weapons.

   _____   I would try to sleep as much as possible.

   _____   I would think about how nice it's going to be when I get home.

   _____   I would make sure I knew where every possible exit was.

L3.   Vividly imagine that, due to a large drop in sales, it is rumored that several people in your department at work will be laid off. Your supervisor has turned in an evaluation of your work for the past year. The decision about lay-off's has been made and will be announced in several days. <u>Check **all** of the statements that might apply to you.</u>

_____   I would talk to my fellow workers to see if they knew anything about what the supervisor's evaluation of me said.

_____   I would review the list of duties for my present job and try to figure out if I had fulfilled them all.

_____   I would go to the movies to take my mind off things.

_____   I would try to remember any arguments or disagreements I might have had with the supervisor that would have lowered his opinion of me.

_____   I would push all thoughts of being laid off out of my mind.

_____   I would tell my spouse that I'd rather not discuss my chances of being laid off.

_____   I would try to think which employees in my department the supervisor might have thought had done the worst job.

_____   I would continue doing my work as if nothing special was happening.

L4.   Vividly imagine that you are on an airplane, 30 minutes from your destination, when the plane unexpectedly goes into a deep dive and then suddenly levels off. After a short time, the pilot announces that nothing is wrong, although the rest of the ride may be rough. You, however, are not convinced that all is well. <u>Check **all** of the statements that might apply to you.</u>

_____   I would carefully read the information provided about safety features in the plane and make sure I knew where the emergency exits were.

_____   I would make small talk with the passenger beside me.

_____   I would watch the end of the movie, even if I had seen it before.

_____   I would call for the stewardess and ask her exactly what the problem was.

_____   I would order a drink or tranquilizer from the stewardess.

_____   I would listen carefully to the engines for unusual noises and would watch the crew to see if their behavior was out of the ordinary.

_____   I would talk to the passenger beside me about what might be wrong.

_____   I would settle down and read a book or magazine or write a letter.

PLEASE CONTINUE ON TO NEXT PAGE

L5. Please indicate how much you agree with the following statements.

		Strongly Disagree				Strongly Agree
a.	If you don't have your health, you don't have anything.	1	2	3	4	5
b.	There are many things I care about more than my health.	1	2	3	4	5
c.	Good health is of only minor importance in a happy life.	1	2	3	4	5
d.	There is nothing more important than good health.	1	2	3	4	5

Please indicate the extent to which each of the following items describes your current family.

		Strongly Disagree				Strongly Agree
M1.	Planning family activities is difficult because we misunderstand each other.	1	2	3	4	5
M2.	In times of crisis we can turn to each other for support.	1	2	3	4	5
M3.	We cannot talk to each other about the sadness we feel.	1	2	3	4	5
M4.	Individuals are accepted for what they are.	1	2	3	4	5
M5.	We avoid discussing our fears and concerns.	1	2	3	4	5
M6.	We can express feelings to each other.	1	2	3	4	5
M7.	There are lots of bad feelings in the family.	1	2	3	4	5
M8.	We feel accepted for what we are.	1	2	3	4	5
M9.	Making decisions is a problem for our family.	1	2	3	4	5
M10.	We are able to make decisions about how to solve problems.	1	2	3	4	5
M11.	We don't get along well together.	1	2	3	4	5
M12.	We confide in each other.	1	2	3	4	5

THANK YOU VERY MUCH.

Women's Health Study

Telephone Questionnaire
Revised 4/19/96

Introduction/Confidentiality Statement

Hello. My name is _____. I'm calling from the Women's Health Study. Thank you for returning your questionnaire. As we had mentioned, we have some questions about your opinions, experiences, and feelings related to cancer and genetic testing, and about your mood. You may have provided some of this information already, but it is important that we update our records. Before we start, I would like to assure you that your name was picked randomly from the pool of people that had volunteered for the genetic studies. We do not have any new information about your status. I would also like to assure you that this interview is confidential and completely voluntary. If we should come to any questions which you do not want to answer or which do not apply to you, just let me know and we will go on to the next question. For quality control purposes, we would like to tape record this interview if that is all right with you. ...May we begin?

Date_____

Length of IW_____

Length of Edit_____

Interviewer_____

CANCER STATUS:

	Breast Cancer Positive
	Ovarian Cancer Positive

1a.   I understand that you (have/have not) been diagnosed with breast cancer.

1. Have Been Diagnosed	5. Have Not

IF R INDICATES "**HAVE BEEN DIAGNOSED**" TO 1a:

1b.   When were you diagnosed?

DATE:_____(month/year)

1c.   On a scale from 1 to 5, with 1 being "not at all distressing" and 5 being "very distressing," how distressed were you by this diagnosis?

Not At All Distressing			Very Distressing	
1	2	3	4	5

2a.   I understand that you (have/have not) been diagnosed with ovarian cancer.

1. Have Been Diagnosed	5. Have Not

IF R INDICATES "**HAVE BEEN DIAGNOSED**" TO 2a:

2b.   When were you diagnosed?

DATE:_____(month/year)

2c.   On a scale from 1 to 5, with 1 being "not at all distressing" and 5 being "very distressing," how distressed were you by this diagnosis?

Not At All Distressing			Very Distressing	
1	2	3	4	5

IF R INDICATES "**HAVE BEEN DIAGNOSED**" TO EITHER 1a OR 2a OR BOTH:

2d.   Have you ever had a second diagnosis of cancer? E.G. AFTER REMISSION, ETC.

1. Yes	5. No

IF R INDICATES "YES" TO 2d:

2e.   When did you receive this second diagnosis?

        DATE:_____(month/year)

2f.   On a scale from 1 to 5, with 1 being "not at all distressing" and 5 being "very distressing," how distressed were you by this diagnosis?

Not At All Distressing		Very Distressing		
1	2	3	4	5

IF R INDICATES "YES" or "HAVE BEEN DIAGNOSED" TO 1a, 2a, OR 2d:

2g.   Is your cancer currently in remission?

1. Yes	5. No

IF R INDICATES "YES" TO 2g:

2h.   How long has your cancer been in remission?

        TIME:_____(months)

2i.   On a scale from 1 to 5, how distressing is it to be a member of a family that may be at risk for breast cancer?

Not At All Distressing		Very Distressing		
1	2	3	4	5

A test is now available which allows women in high-risk families to find out if they (personally) have the alteration(s) of a gene (BRCA1) associated with increased risk for breast and ovarian cancer.

2j.   On a scale from 1 to 5, how distressing is it to be given the opportunity to be tested for this gene?

Not At All Distressing		Very Distressing		
1	2	3	4	5

2k.   On a scale from 1 to 5, 1 being "not at all," and 5 being "very much," to what extent do you welcome the opportunity to be tested?

Not At All		Very Much		
1	2	3	4	5

21. On a scale from 1 to 5, with 1 being "not at all distressing," and 5 being "very distressing," how distressing would it be to have the test and discover that you have the altered gene that is associated with an increased risk for breast and ovarian cancer?

Not At All Distressing			Very Distressing	
1	2	3	4	5

2m. Using the same scale, how distressing would it be to have the test and discover that you do not have the altered gene?

Not At All Distressing			Very Distressing	
1	2	3	4	5

FOR QUESTIONS 3-5b, INDICATE THE NUMBER OF RELATIVES AFFECTED BY CANCER - ENTER ZERO FOR NO CANCER DIAGNOSIS IN A CATEGORY

		Mother	Sister(s)	Daughter(s)	First Aunt(s)	Grandmother(s)	First Cousin(s)
3.	Which of your relatives has had breast cancer?						
4.	Which of your relatives has had ovarian cancer?						
5a.	Have any of your relatives died of breast cancer?						
5b.	Have any of your relatives died of ovarian cancer?						

NOT INCLUDING GREAT-GRANDMOTHERS

RELATIVES AFFECTED BY CANCER:
    REPEAT THIS SECTION (QUESTIONS 0-10) FOR EACH RELATIVE R INDICATES AFFECTED BY CANCER

Now I am going to ask you about your experiences with cancer among your close relatives.

Let's Start with _____(relationship)

0.   Is she from your mother or your father's side of the family?

Mother's	Father's
1	2

1.   When was she diagnosed?

DATE:_____(year)

   1a.   On a scale from 1 to 5, how distressed were you by her diagnosis?

Not At All Distressed			Very Distressed		Didn't Know IF VOL.
1	2	3	4	5	6

2.   Is she alive?

1. Yes	5. No

IF R ANSWERS "NO" TO 2:

   2a.   Did she die of the cancer or something related to it?
         SCORE R's BELIEF

1. Yes	5. No

IF R ANSWERS "YES" To 2a:

     2b.   When did she die?

         DATE:_____(year)

     2c.   How old was she when she died?

         AGE:_____(years)

     2d.   How old were you when she died?

         AGE:_____(years)

2e.   On a scale from 1 to 5, how distressed were you by this news?

Not At All Distressed			Very Distressed		Didn't Know IF VOL.
1	2	3	4	5	6

3.   What treatment did she receive? SCORE EACH SURGERY SEPARATELY

Treatment:	1. Yes	5. No
A. Lumpectomy		
B. Unilateral Mastectomy		
C. Bilateral Mastectomy		
D. Oophorectomy (ovaries removed)		
E. Hysterectomy		
F. Chemotherapy		
G. Radiation		
H. Hormonal Therapy		
I. Immunotherapy		
J. Don't Know		
K. Other		
L. None		

IF BOTH BREASTS REMOVED IN TWO SEPARATE SURGERIES SCORE **YES** FOR UNILATERAL AND **YES** FOR BILATERAL

On a scale of 1 to 5, with 1 being "not at all" and 5 being "very much,"

		Not At All				Very Much	Didn't Know IF VOL.
4.	At the time of the illness, how (emotionally) close were you to your (relative)?	1	2	3	4	5	6

On a scale of 1 to 5, with 1 being "not at all" and 5 being "very much",

5.   At the time of her illness, how aware were you of the following aspects of your (relative's) condition?

		Not at All				VeryM uch -	Didn't KnowI f Vol
A.	Diagnosis	1	2	3	4	5	6
B.	Course of illness	1	2	3	4	5	6
C.	Prognosis (what could be expected)	1	2	3	4	5	6
D.	Her pain or suffering	1	2	3	4	5	6
E.	Side effects of treatment	1	2	3	4	5	6
F.	Impairment (not being able to do what she once did) and disruption of her life	1	2	3	4	5	6
G.	How involved were you in the treatment and care of your (relative)?	1	2	3	4	5	6

6. At the time of her illness, did you help care for her in any of the following ways?

		1. Yes	5. No
A.	Accompanied to appointments		
B.	Visited at hospital		
C.	Did chores for her		
D.	Provided comfort and emotional support		

On a scale of 1 to 5, with 1 being "not at all" and 5 being "very much,"

		Not At All				Very Much	Didn't Know IF VOL.
7.	At that time, to what extent did you talk with her about her experience?	1	2	3	4	5	6
8.	At that time, how upsetting was her experience with cancer for you? [OVERALL]	1	2	3	4	5	6

		Much More Distant	A Little More Distant	No Change	A Little Closer	A Lot Closer
9.	At that time, how did your (relative's) illness affect your relationship with other family members? Did it make you...[READ OPTIONS]	1	2	3	4	5

On a scale of 1 to 5, with 1 being "not at all" and 5 being "very much,"

		Not At All				Very Much	Didn't Know IF VOL.
10.	How much has your experience with your (relative) affected the way you think about your own risk for cancer and options for dealing with it? [CURRENTLY]	1	2	3	4	5	6

REPEAT QUESTIONS 0-10 (STARTING ON PAGE 5) FOR ANY ADDITIONAL RELATIVES

---

11. Now I'd like to find out how you keep up with new information about breast cancer (including prevention, detection, and treatment). I'm going to read you a list of sources; On a scale from 1 to 5, with 1 being "not at all" and 5 being "very much," how much do you rely on... REPEAT AS NECESSARY

		Not At All				Very Much
a.	Your OB/GYN	1	2	3	4	5
b.	Your family physician	1	2	3	4	5
c.	Another physician (Specialty_____)	1	2	3	4	5
d.	Family Members [WHO GAVE INFO]	1	2	3	4	5
e.	Friends [WHO GAVE INFO]	1	2	3	4	5
f.	Newspapers, television, and radio	1	2	3	4	5
g.	Popular women's magazines	1	2	3	4	5
h.	Other (specify_____)	1	2	3	4	5

READ OPTIONS		Not At All	A Little	Somewhat	A Great Deal
12.	How much do you watch for new information in the media (newspaper, magazines, television, radio)?	1	2	3	4
13.	How much do you try to avoid this information in the media?	1	2	3	4
14.	How much confidence do you have in the accuracy of such information in the media?	1	2	3	4

15bi. Are you aware of the gene (BRCA1) associated with increased risk for early onset breast cancer?

1. Yes	5. No

IF R ANSWERS "YES" TO 15b:		Hopeful	Relieved	Anxious or Fearful	Depressed
15c.	Which of the following best describes how you felt when you heard about the discovery of this gene? READ OPTIONS - R MAY CHOOSE ONLY ONE	1	2	3	4

IF R ANSWERS "YES" TO 15b:		Not At All	A Little	Somewhat	A Great Deal
15d.	How much did you discuss this development with your mother and/or your sisters? READ OPTIONS	1	2	3	4
15e.	IF R IS MARRIED/PARTNERED: How much have you discussed this development with your (spouse/partner)? READ OPTIONS	1	2	3	4
15f.	IF R HAS CHILDREN: How much have you discussed this development with your children? READ OPTIONS	1	2	3	4

15g.   IF R IS CANCER POSITIVE:
        Women who are living with breast cancer report various levels of distress.
        How often do you feel distressed about living with breast cancer?

        IF R IS CANCER NEGATIVE:
        Women who are at risk for breast cancer report various levels of distress.
        How often do you feel distressed about your risk for breast cancer?

        READ OPTIONS

Never	Rarely	Sometimes	Often
1	2	3	4

15h.   Thinking about your family's risk for breast cancer and your own diagnosis/risk, what has been the most distressing part?

        _____

        _____

15i.   On a scale from 1 to 5, how distressing is this?

Not At All Distressing		Very Distressing		
1	2	3	4	5

FOR WOMEN WITH LIVING SISTERS:
        SKIP IF R HAS NO LIVING SISTERS

Now I'm going to ask some questions about your relationship with your sisters.

16a.   IF R IS CANCER POSITIVE:
        How often do you discuss living with breast cancer with your sisters?

        IF R IS CANCER NEGATIVE:
        How often do you discuss your risk for breast cancer with your sisters?

        READ OPTIONS

Never	Rarely	Sometimes	Often
1	2	3	4

        IF R ANSWERS "NEVER" TO 16a, DO NOT ASK 16b-d

16b. When you have these discussions, who generally initiates them?

You	Your Sisters	Equally [IF VOLUNTEERED]
1	2	3

16c. How satisfied are you with these discussions?

READ OPTIONS

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

16d. What is helpful to you when talking with your sisters about your risk for breast cancer?
SCORE ALL THAT APPLY - R CAN CHOOSE MORE THAN ONE - SCORE WHAT IS
CURRENTLY HELPFUL, NOT WHAT THEY BELIEVE MIGHT BE HELPFUL

		1. Yes	5. No
1.	Receiving new information.		
2.	The opportunity to express your feelings.		
3.	Receiving comfort or being taken care of.		
4.	Feeling understood.		
5.	Knowing you are not alone.		

16e. Overall, how important is your sister's opinion in your decision whether or not to be tested for the breast cancer gene?

READ OPTIONS

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

16f.   In making decisions about what to do to reduce your risk of breast cancer in the future, how important is your sister's opinion?
IF R INSISTS THAT THERE ARE NO MORE DECISIONS TO BE MADE, CODE **1**

READ OPTIONS

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

16g.   Considering **only the positive feelings** you have toward your sisters, and **ignoring the negative ones**, please rate how positive these feelings are. Use a scale of 1 to 10, with 1 being "not at all positive" and 10 being "extremely positive." SCORE GENERAL FEELING TOWARD PERSON, NOT JUST REGARDING CANCER

Not At All Positive							Extremely Positive		
1	2	3	4	5	6	7	8	9	10

16h.   Considering **only the negative feelings** you have toward your sisters, and **ignoring the positive ones**, please rate how negative these feelings are. Use a scale of 1 to 10, with 1 being "not at all negative" and 10 being "extremely negative." SCORE GENERAL FEELING TOWARD PERSON, NOT JUST REGARDING CANCER

Not At All Negative							Extremely Negative		
1	2	3	4	5	6	7	8	9	10

FOR WOMEN WITH LIVING MOTHERS:
SKIP IF R's MOTHER IS NOT LIVING

Now I am going to ask some questions about your relationship with your mother.

17a.   IF R IS CANCER POSITIVE:
How often do you discuss living with breast cancer with your mother?

IF R IS CANCER NEGATIVE:
How often do you discuss your risk for breast cancer with your mother?

READ OPTIONS

Never	Rarely	Sometimes	Often
1	2	3	4

IF R ANSWERS "NEVER" TO 17a, DO NOT ASK 17b-d

17b.   When you have these discussions, who generally initiates them?

You	Your Mother	Equally [IF VOLUNTEERED]
1	2	3

17c.   How satisfied are you with these discussions?

READ OPTIONS

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

17d.   What is helpful to you when talking with your mother about your risk for breast cancer?
SCORE ALL THAT APPLY - R CAN CHOOSE MORE THAN ONE - SCORE WHAT IS
CURRENTLY HELPFUL, NOT WHAT THEY BELIEVE MIGHT BE HELPFUL

	1. Yes	5. No
1. Receiving new information.		
2. The opportunity to express your feelings.		
3. Receiving comfort or being taken care of.		
4. Feeling understood.		
5. Knowing you are not alone.		

17e.   Overall, how important is your mother's opinion in your decision whether or not to be tested for the breast cancer gene?

READ OPTIONS

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

17f. In making decisions about what to do to reduce your risk of breast cancer in the future, how important is your mother's opinion?
IF R INSISTS THAT THERE ARE NO MORE DECISIONS TO BE MADE, CODE 1

READ OPTIONS

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

17g. Considering **only the positive feelings** you have toward your mother, and **ignoring the negative ones,** please rate how positive these feelings are. Use a scale of 1 to 10, with 1 being "not at all positive" and 10 being "extremely positive." SCORE GENERAL FEELING TOWARD PERSON, NOT JUST REGARDING CANCER

Not At All Positive							Extremely Positive		
1	2	3	4	5	6	7	8	9	10

17h. Considering **only the negative feelings** you have toward your mother, and **ignoring the positive ones,** please rate how negative these feelings are. Use a scale of 1 to 10, with 1 being "not at all negative" and 10 being "extremely negative." SCORE GENERAL FEELING TOWARD PERSON, NOT JUST REGARDING CANCER

Not At All Negative							Extremely Negative		
1	2	3	4	5	6	7	8	9	10

FOR WOMEN WHO ARE MARRIED OR LIVING WITH A PARTNER:
SKIP IF R IS NOT MARRIED/PARTNERED

Now I am going to ask you some questions about your relationship with your (husband/partner).

18a. IF R IS CANCER POSITIVE:
How often do you discuss living with breast cancer with your husband/partner?

IF R IS CANCER NEGATIVE:
How often do you discuss your risk for breast cancer with your husband/partner?

READ OPTIONS

Never	Rarely	Sometimes	Often
1	2	3	4

IF R ANSWERS "NEVER" TO 18a, DO NOT ASK 18b-d

18b.   When you have these discussions, who generally initiates them?

You	Your Husband/ Partner	Equally [IF VOLUNTEERED]
1	2	3

18c.   How satisfied are you with these discussions?

READ OPTIONS

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

18d.   What is helpful to you when talking with your husband/partner about your risk for breast cancer?
SCORE ALL THAT APPLY - R CAN CHOOSE MORE THAN ONE - SCORE WHAT IS
CURRENTLY HELPFUL, NOT WHAT THEY BELIEVE MIGHT BE HELPFUL

	1. Yes	5. No
1. Receiving new information.		
2. The opportunity to express your feelings.		
3. Receiving comfort or being taken care of.		
4. Feeling understood.		
5. Knowing you are not alone.		

18e.   Overall, how important is your husband/partner's opinion in your decision whether or not to be tested for the breast cancer gene?

READ OPTIONS

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

18f. In making decisions about what to do to reduce your risk of breast cancer in the future, how important is your (husband's/partner's) opinion?
IF R INSISTS THAT THERE ARE NO MORE DECISIONS TO BE MADE, CODE 1

READ OPTIONS

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

18g. Considering **only the positive feelings** you have toward your husband/partner, and **ignoring the negative ones**, please rate how positive these feelings are. Use a scale of 1 to 10, with 1 being "not at all positive" and 10 being "extremely positive." SCORE GENERAL FEELING TOWARD PERSON, NOT JUST REGARDING CANCER

Not At All Positive							Extremely Positive		
1	2	3	4	5	6	7	8	9	10

18h. Considering **only the negative feelings** you have toward your husband/partner, and **ignoring the positive ones**, please rate how negative these feelings are. Use a scale of 1 to 10, with 1 being "not at all negative" and 10 being "extremely negative." SCORE GENERAL FEELING TOWARD PERSON, NOT JUST REGARDING CANCER

Not At All Negative							Extremely Negative		
1	2	3	4	5	6	7	8	9	10

FOR WOMEN WITH LIVING DAUGHTER/S:
SKIP IF R HAS NO LIVING DAUGHTER/S

Now I am going to ask you some questions about your relationship with your daughter/s.

19i. What are the ages of your daughters?

_____ _____ _____

_____ _____ _____

_____ _____ _____

19ii. In general, do you discuss family history and risk for breast cancer with your daughter/s?

1. **Yes**	5. **No**

19e. Overall, how important is/are your daughters' opinion in your decision whether or not to be tested for the breast cancer gene?

READ OPTIONS

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

19f. In making decisions about what to do to reduce your risk of breast cancer in the future, how important is/are your daughter's opinion/s?
IF R INSISTS THAT THERE ARE NO MORE DECISIONS TO BE MADE, CODE 1

READ OPTIONS

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

19g. Considering **only the positive feelings** you have toward your daughters, and **ignoring the negative ones**, please rate how positive these feelings are. Use a scale of 1 to 10, with 1 being "not at all positive" and 10 being "extremely positive." SCORE GENERAL FEELING TOWARD PERSON, NOT JUST REGARDING CANCER

Not At All Positive							Extremely Positive		
1	2	3	4	5	6	7	8	9	10

19h. Considering **only the negative feelings** you have toward your daughters, and **ignoring the positive ones**, please rate how negative these feelings are. Use a scale of 1 to 10, with 1 being "not at all negative" and 10 being "extremely negative." SCORE GENERAL FEELING TOWARD PERSON, NOT JUST REGARDING CANCER

Not At All Negative							Extremely Negative		
1	2	3	4	5	6	7	8	9	10

FOR WOMEN WITH CHILDREN:
SKIP IF R HAS NO CHILDREN

19iii. If you should choose to obtain genetic testing, do you intend to inform your children of the results?

1. Yes	5. No	7. Undecided [IF VOLUNTEERED]

FOR ALL WOMEN:

20. If you were to find that you were a carrier for BRCA1, the gene for increased risk of breast cancer, what options would you consider?

_____

_____

_____

_____

[DONE]

B.II. Proband Interim Questionnaire

WOMEN'S HEALTH STUDY
Interim Questionnaire - 1999

GENETIC TESTING-SECTION 1

1. Have you contributed a blood or tissue sample to the <u>GENETIC TESTING</u> portion of the research project?

    ☐ Yes   ☐ No   **B21.**

2. Has any member of your family contributed a blood or tissue sample to the <u>GENETIC TESTING</u> portion of the research project?

    ☐ Yes   ☐ No   ☐ I Don't Know   **B22.**

3. Have you or any family members received notification that genetic results are available?   **B23.**

There Has Been No Notification	Results Are Available	Results Are NOT YET Available	Results will NEVER BE Available, I am Not Eligible

4. Have **you** received results of genetic testing for breast or ovarian cancer?

    ☐ Yes   ☐ No (Skip to Question 5)

    4a.   When did this occur?   _____(mo/yr)

    4b.   What was the source of this information?
           ☐ University of Pennsylvania   ☐ Independent Testing   ☐Other:_____

    4c.   What were the results? (Optional)

    _____

5. Has **any family member** received results of genetic testing for breast or ovarian cancer?

    ☐ Yes   ☐ No (Skip to Next Section)   ☐ Don't Know (Skip to Next Section)

    5a.   When did this occur?   _____(mo/yr)

    5b.   What was the source of this information?
           ☐ University of Pennsylvania   ☐ Independent Testing   ☐Other:_____

    5c.   What were the results? (Optional)

    _____

    5d.   Can you infer your genetic results from your relative's results (i.e., Have you been able to figure out whether you are positive or negative for the gene that conveys higher risk for breast cancer with this information?)

    ☐ Yes   ☐ No   ☐ Don't Know

PERSONAL ATTITUDES SECTION

1. For each of these statements, please indicate the extent to which you agree or disagree by circling the appropriate number. There are no right or wrong answers. We are only interested in your opinions.

		Strongly Disagree				Strongly Agree	
a.	If you don't have your health, you don't have anything.	1	2	3	4	5	L5a.
b.	There are many things I care about more than my health.	1	2	3	4	5	L5b.
c.	Good health is of only minor importance in a happy life.	1	2	3	4	5	L5c.
d.	There is nothing more important than good health.	1	2	3	4	5	L5d.
e.	In uncertain times, I usually expect the best.	1	2	3	4	5	E1.
f.	It's easy for me to relax.	1	2	3	4	5	E2.
g.	If something can go wrong for me, it will.	1	2	3	4	5	E3.
h.	I always look on the bright side of things.	1	2	3	4	5	E4.
i.	I'm always optimistic about my future.	1	2	3	4	5	E5.
j.	I enjoy my friends a lot.	1	2	3	4	5	E6.
k.	It's important for me to keep busy.	1	2	3	4	5	E7.
l.	I hardly ever expect things to go my way.	1	2	3	4	5	E8.
m.	Things never work out the way I want them to.	1	2	3	4	5	E9.
n.	I don't get upset too easily.	1	2	3	4	5	E10.
o.	I'm a believer in the idea that "every cloud has a silver lining."	1	2	3	4	5	E11.
p.	I rarely count on good things happening to me.	1	2	3	4	5	E12.

2

GENETIC TESTING-SECTION 2

1.   A medical test may soon be available that allows some women to learn their genetic
     risk for developing a form of breast and ovarian cancer that runs in families. Even
     though you have been diagnosed with breast cancer, would you consider taking
     the genetic test to learn if your cancer is the type that runs in families?
     (Please check one response).   B15.

   (1)._____   I will definitely take the test immediately when it becomes available.

   (2)._____   I will definitely take the test, but I am not sure if immediately.

   (3)._____   I will probably take the test immediately when it becomes available.

   (4)._____   I will probably take the test, but not immediately.

   (5)._____   I am undecided whether I will take the test

   (6)._____   I will probably not take the test.

   (7)._____   I will definitely not take the test.

2.   On the following scale, indicate how distressing it is for you to know that   B66.
     you may be at increased risk for breast cancer because of your family history?

Not At All Distressing				Very Distressing
1	2	3	4	5

3.   How distressing it is to be given the opportunity to be tested for the BRCA-1 gene, B67.
     the altered gene associated with increased risk for breast cancer?

Not At All Distressing				Very Distressing
1	2	3	4	5

4.   How distressed do you expect to be when you actually get tested for the BRCA-1   B68.
     gene (before you receive results)?

Not At All Distressed				Very Distressed
1	2	3	4	5

5.   How distressed would you be if you took the test and found that you had the   B69.
     BRCA-1 gene?

Not At All Distressed				Very Distressed
1	2	3	4	5

6. How distressed would you be if you took the test and found that you **did not have** the BRCA-1 gene?

Not At All Distressed				Very Distressed
1	2	3	4	5

7. Overall, to what extent do you welcome the opportunity to be tested for the BRCA-1 gene?

Not At All				Very Much So
1	2	3	4	5

		Not At All				All The Time	
8.	How often do you worry about again developing breast cancer?	1	2	3	4	5	B27.
9.	To what extent do these worries interfere with your every day life?	1	2	3	4	5	B28.
10.	How often do you worry about having the altered gene carrying risk for breast cancer ?	1	2	3	4	5	B29.
11.	To what extent do these worries you have about having this altered gene interfere with your every day life?	1	2	3	4	5	B30.

12. Before your diagnosis of breast cancer, how likely did you think you were to develop breast cancer, compared to other women? **(Please circle one)**

Much Less Likely				Much More Likely
1	2	3	4	5

13. When was the last time you had a mammography?

_____Month _____Year   (-8) ☐ This question does not apply because of surgery.

14. How many times have you conducted a breast self-examinations (BSE) in the past six months?

_____times   (-8) ☐ This question does not apply because of surgery.

4

15. How confident are you that you will perform breast self examination (BSE) ---

15a. --as **frequently** as needed? (-8) ☐ Does Not Apply Because of Surgery   B34a.

       Not at All   Very Much So
         1   2   3   4   5   6   7

15b. --as **carefully and competently** as needed?   B34b.

                                (-8) ☐ Does Not Apply Because of Surgery

       Not at All   Very Much So
         1   2   3   4   5   6   7

For each of the following areas of your life, you will be asked to make **two** ratings. First, indicate how much these decisions have been affected by *the possibility that you have an increased risk for breast cancer* (based on your family history). Second, how much would these decisions be affected by *the results of genetic testing* ?

1	2	3	4	5
Not at all affected				**Very much affected**

		Have been affected by being at risk for breast cancer					Would be affected by the results of genetic testing					
16.	Decisions about having children	1	2	3	4	5	1	2	3	4	5	B. B.
17.	Decisions about form of birth control	1	2	3	4	5	1	2	3	4	5	B. B.
18.	Decisions about which steps to take to prevent the recurrence of breast cancer	1	2	3	4	5	1	2	3	4	5	B. B.
19.	Decisions about work and career	1	2	3	4	5	1	2	3	4	5	B. B.
20.	Decisions about savings and financial planning	1	2	3	4	5	1	2	3	4	5	B. B.
21.	Decisions about plans for the future	1	2	3	4	5	1	2	3	4	5	B. B.

5

22. **Answer the following question only if you have (biological) daughters.**

☐ Does Not Apply   B41.
    (Skip to Next Section, Life Events)

		Have been affected by being at high risk for breast cancer					*Would be affected by the results of genetic testing*					
a.	Plans for your daughter's future	1	2	3	4	5	1	2	3	4	5	B42: B42

LIFE EVENTS SECTION

1. Have any of the following events happened to you in the past six months?   D1(a-m)
   (Check All That Apply)

a. ☐ You retired, were fired, or laid off from work.

b. ☐ You were unemployed and looking for work.

c. ☐ Your spouse retired, was fired, or laid off from work.

d ☐ Your spouse was unemployed and looking for work.

e. ☐ You had problems with the police or court.

f. ☐ You got into serious financial difficulties.

g. ☐ A close family member was seriously ill or injured.

h. ☐ You had a marital separation or divorce.

i. ☐ You had serious troubles with relatives or close friends.

j. ☐ Your spouse had troubles or difficulties with relatives or close friends.

k. ☐ A close family member died.

l. ☐ A close friend or relative died.

m. ☐ You were seriously ill or injured.

MARRIAGE SECTION

The following questions apply to persons who are <u>married or living with a partner</u>. *If you are not married or living with a partner, check the appropriate box and please skip to the Next Section, MOOD.*

Not married or living with a partner ☐   **Ha**.

Most persons have disagreements in their relationships. Please check the appropriate box to indicate the extent of agreement or disagreement experienced between you and your partner **DURING THE PAST MONTH**, regarding.

		Always Agree	*Almost Always Agree*	*Occasionally Disagree*	*Frequently Disagree*	*Almost Always Disagree*	*Always Disagree*	
1.	Religious matters	6	5	4	3	2	1	**H3**.
2.	Demonstration of affection	6	5	4	3	2	1	**H4**.
3.	Sex relations	6	5	4	3	2	1	**H6**.
4.	Conventionality (correct or proper behavior)	6	5	4	3	2	1	**H7**.
5.	Making major decisions	6	5	4	3	2	1	**H12**.
6.	Career decisions	6	5	4	3	2	1	**H15**.

		All of the time	*Most of the time*	*More often than most*	*Occasionally*	*Rarely*	*Never*	
7.	How often do you discuss or have you considered divorce, separation, or terminating your relationship?	1	2	3	4	5	6	**H16**.
8.	Do you ever regret that you married (or are living together)?	1	2	3	4	5	6	**H20**.
9.	How often do you and your husband/partner quarrel?	1	2	3	4	5	6	**H21**.
10.	How often do you and your husband/partner "get on each other's nerves?"	1	2	3	4	5	6	**H22**.

7

		All of Them	Most of Them	Some of Them	Very few of Them	None of Them	
11.	Do you and your husband/partner engage in outside interests together?	5	4	3	2	1	H24.

How often would you say the following events occur between you and your husband/partner?

		Never	Less than once a month	About twice a month	About twice a week	Once a day	More Often	
12.	Have a stimulating exchange of ideas	1	2	3	4	5	6	H25.
13.	Calmly discuss something	1	2	3	4	5	6	H27.
14.	Work together on a project	1	2	3	4	5	6	H28.

15. Considering **only the positive feelings** you have toward your husband/partner, and **ignoring the negative ones**, please rate how positive these feelings are: H33.

Not At All Positive								Extremely Positive	
1	2	3	4	5	6	7	8	9	10

16. Considering **only the negative feelings** you have toward your husband/partner, and **ignoring the positive ones**, please rate how negative these feelings are: H34.

Not At All Negative								Extremely Negative	
1	2	3	4	5	6	7	8	9	10

17. The following questions concern your husband's involvement in your health care.

		Never				Very Often	
a.	How often does your husband/partner go with you to your appointments with doctors?	1	2	3	4	5	H35a.
b.	How often does your husband/partner talk with your doctor or other medical personnel about your risk for breast cancer?	1	2	3	4	5	H35b.
c.	How often does your husband/partner keep track of what you need to do about your risk for breast cancer?	1	2	3	4	5	H35c.
d.	How often does your husband/partner change his activities to assist you in your health care?	1	2	3	4	5	H35d.

18. Has your husband/partner attended individual, family or group sessions to become informed about your risk for breast cancer and what can be done?   H36.

(1) Yes ☐   (5) No ☐

19. How much contact has your husband/partner had with medical personnel concerning your risk for breast cancer.   H37.

Very Little
or None   A lot
1   2   3   4   5   6   7

20. Do you feel your husband/partner is adequately informed concerning your risk for breast cancer and what can be done about it?   H38.

Not at All   Very Much
1   2   3   4   5   6   7

21. To what extent are you satisfied with your husband/partner's involvement in your health care?   H39.

Not at All   Very Much
1   2   3   4   5   6   7

MOOD SECTION

1. Have you **ever in your lifetime** had two weeks or more when nearly every day you felt sad, blue, or depressed <u>or</u> in which you lost all interest in things like work or hobbies or things you usually liked to do for fun?

   I14

   (1) ☐ Yes   (5) ☐ No (Skip to Question 2)

   1a. If there was such a two-week period, did your work or relationships suffer?   I14a.

   (1) ☐ Yes   (5) ☐ No

   1b. If there was such a two-week period, did you get counseling or psychotherapy?   I14b.

   (1) ☐ Yes   (5) ☐ No

   1c. If there was such a two-week period, did you get medication for this condition?   I14c.

   (1) ☐ Yes   (5) ☐ No

2. In **the past 6 months**, have you had two weeks or more when nearly every day you felt sad, blue, or depressed <u>or</u> in which you lost all interest in things like work or hobbies or things you usually liked to do for fun?   I12.

   (1) ☐ Yes   (5) ☐ No (Skip to Question 3)

   2a. If there was such a two-week period in **the past 6 months**, did your work or relationships suffer?   I12a.

   (1) ☐ Yes   (5) ☐ No

   2b. If there was such a two-week period in **the past 6 months**, did you get counseling or psychotherapy?   I12b.

   (1) ☐ Yes   (5) ☐ No

   2c. If there was such a two-week period in **the past 6 months**, did you get medication for this condition?   I12c.

   (1) ☐ Yes   (5) ☐ No

3. Are you **currently** receiving counseling, psychotherapy or medication for depression or emotional problems?   I13.

   (1) ☐ Yes   (5) ☐ No

10

Symtoms of Strain Section

LISTED BELOW ARE SOME SYMPTOMS OF STRAIN THAT PEOPLE SOMETIMES HAVE. *Please Read Each One Carefully And Check The Answer Which Best Reflects How Much That Symptom Has Bothered You During the Past Three Months.*

		Not at all	A little	Quite a bit	Extremely	
1.	Suddenly scared for no reason	1	2	3	4	K1.
2.	Feeling fearful	1	2	3	4	K2.
3.	Faintness, dizziness, or weakness	1	2	3	4	K3.
4.	Nervousness or shakiness inside	1	2	3	4	K4.
5.	Heart pounding or racing	1	2	3	4	K5.
6.	Trembling	1	2	3	4	K6.
7.	Feeling tense or keyed up	1	2	3	4	K7.
8.	Headaches	1	2	3	4	K8.
9.	Spells of terror or panic	1	2	3	4	K9.
10.	Feeling restless, can't sit still	1	2	3	4	K10.
11.	Feeling low in energy--slowed down	1	2	3	4	K11.
12.	Blaming yourself for things	1	2	3	4	K12.
13.	Crying easily	1	2	3	4	K13.
14.	Loss of sexual interest or pleasure	1	2	3	4	K14.
15.	Poor appetite	1	2	3	4	K15.
16.	Difficulty falling asleep, staying asleep	1	2	3	4	K16.
17.	Feeling hopeless about the future	1	2	3	4	K17.
18.	Feeling blue	1	2	3	4	K18.
19.	Feeling lonely	1	2	3	4	K19.
20.	Feeling trapped or caught	1	2	3	4	K20.
21.	Worrying too much about things	1	2	3	4	K21.
22.	Feeling no interest in things	1	2	3	4	K22.
23.	Thoughts of ending your life	1	2	3	4	K23.
24.	Feeling everything is an effort	1	2	3	4	K24.
25.	Feelings of worthlessness	1	2	3	4	K25.

COPING SECTION

1. Sometimes people can find unexpected benefits in difficulties. We are interested in the ways in which you might have made positive use of your risk for breast cancer. For each of the statements below, indicate the degree to which your life is affected <u>positively</u> by your risk of breast cancer.

		Not At All	A Very Small Degree	A Small Degree	A Moderate Degree	A Great Degree	A Very Great Degree	
a.	My priorities about what is important in life.	1	2	3	4	5	6	L6a.
b.	I'm more likely to try to change things which need changing.	1	2	3	4	5	6	L6b.
c.	An appreciation for the value of my own life.	1	2	3	4	5	6	L6c.
d.	A feeling of self-reliance.	1	2	3	4	5	6	L6d.
e.	A better understanding of spiritual matters.	1	2	3	4	5	6	L6e.
f.	Knowing that I can count on people in times of troubles.	1	2	3	4	5	6	L6f.
g.	A sense of closeness with others.	1	2	3	4	5	6	L6g.
h.	Knowing I can handle difficulties.	1	2	3	4	5	6	L6h.
i	A willingness to express my emotions.	1	2	3	4	5	6	L6i.
j.	Being able to accept the way things work out.	1	2	3	4	5	6	L6j.
k.	Appreciating each day.	1	2	3	4	5	6	L6k.
l.	Having compassion for others.	1	2	3	4	5	6	L6l.
m.	I'm able to do better things with my life.	1	2	3	4	5	6	L6m.
n.	New opportunities are available which wouldn't have been otherwise.	1	2	3	4	5	6	L6n.

2. This set of questions deals with ways you've been coping with the stress in your life that comes with being at risk for breast cancer. There are many ways people try to deal with problems. Obviously, different people deal with things in different ways, but we are interested in how you've tried to deal with it. Each item says something about a particular way of coping. We want to know *to what extent* you've been doing what the item says, how *much* or how *frequently*. Don't answer on the basis of whether it seems to be working but just whether or not you're doing it. Use these response choices below and try not to let one answer influence another. Make your answers as true FOR YOU as you can.

		I haven't been doing this at all 1	*I've been doing this a little bit* 2	*I've been doing this some* 3	*I've been doing this a lot* 4	
a.	I've been turning to work or other activities to take my mind off things.	1	2	3	4	L7a.
b.	I've been concentrating my efforts on doing something about my situation.	1	2	3	4	L7b.
c.	I've been saying to myself "this isn't possible."	1	2	3	4	L7c.
d.	I've been using alcohol or other drugs to make myself feel better.	1	2	3	4	L7d.
e.	I've been getting emotional support from others.	1	2	3	4	L7e.
f.	I've been giving up trying to deal with it.	1	2	3	4	L7f.
g.	I've been taking action to try to make the situation better.	1	2	3	4	L7g.
h.	I've been refusing to believe that it is possible that I have an altered gene.	1	2	3	4	L7h.
i.	I've been saying things to let my unpleasant feelings escape.	1	2	3	4	L7i.
j.	I've been using alcohol or other drugs to help me get through it.	1	2	3	4	L7j.
k.	I've been trying to see it in a different light, to make it seem more positive.	1	2	3	4	L7k.
l.	I've been trying to come up with a strategy about what to do.	1	2	3	4	L7l.
m.	I've been getting comfort and understanding from someone.	1	2	3	4	L7m

13

		I haven't been doing this at all 1	I've been doing this a little bit 2	I've been doing this some 3	I've been doing this a lot 4	
n.	I've been giving up the attempt to cope.	1	2	3	4	**L7n.**
o.	I've been accepting the possibility that I might have an altered gene.	1	2	3	4	**L7o.**
p.	I've been expressing my negative feelings.	1	2	3	4	**L7p.**
q.	I've been trying to find comfort in my religion or spiritual beliefs.	1	2	3	4	**L7q.**
r.	I've been learning to live with the possibility that I might have the gene.	1	2	3	4	**L7r.**
s.	I've been thinking hard about what steps to take.	1	2	3	4	**L7s.**
t.	I've been praying or meditating.	1	2	3	4	**L7t.**
u.	I've been making fun of the situation.	1	2	3	4	**L7u.**

3.   The following items are to be answered only by those women who are _married or living with a partner_.
(-8) ☐ Not married or living with a partner   **L8.**
(Skip to Last Section on page 15, Background Data)

		I haven't been doing this at all 1	I've been doing this a little bit 2	I've been doing this some 3	I've been doing this a lot 4	
a.	I've been denying or hiding my anger around my husband/partner.	1	2	3	4	**L8a.**
b.	I've been denying or hiding my worries around my husband/partner.	1	2	3	4	**L8b.**
c.	I've been avoiding talking about my problems around my husband/partner.	1	2	3	4	**L8c.**
d.	I've acted more positive around my husband/partner than I feel.	1	2	3	4	**L8d.**

BACKGROUND DATA

These are a few questions about your religious background, that we forgot to ask on the original questionnaire.

1.   Religion: .   Catholic   (1) ☐   Protestant   (4) ☐   **A3.**

Jewish   (2) ☐   Buddhist   (5) ☐

Muslim   (3) ☐   Other   (6) ☐

None   (7) ☐

1a.   How often do you attend religious services?   **A3a.**
(1)   (5)
☐ Less Often Than Once a Month   ☐   A Few Times A Month or More

1b.   How important are religious and spiritual beliefs in your life?   **A3b.**

Not at All   Very Important
1   2   3   4   5

Once Again, We thank you for all of your valued participation in this study.

B.IV. Supplemental Surveys

Qualitative Risk Supplemental Questions
Social Relationships Supplemental Surveys – (Affected, Unaffected, & Men)

QUALITATIVE RISK SUPPLEMENTAL QUESTIONS

1. Using the same scale from 0% to 100% chance, what do you believe your risk is of developing breast cancer (*again*) **at some point in your lifetime**? _____%

2. We are trying to understand how people decide on their level of risk. Can you tell me what factors went in to your rating your risk as _____? In other words, what kinds of things did you think about to decide on that number?

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

Social Relationships Supplemental Survey for Women (A)

Part 1. General Information

1. If you **are** currently married, what was the date of your current marriage?
   Month _____   Year _____

2. Is this your first marriage?   (1) ☐ Yes   (5) ☐ No

3. How many children do you have? _____

   a.   Number of children living at home   _____

   b.   Number who are under age 6   _____

4. Are you currently working for pay outside the home?   (1) ☐ Yes   (5) ☐ No

   a. If **yes**, about how many hours per week are you working for pay?

Less than 10	10-20	21-30	31-40	41 or more
☐	☐	☐	☐	☐

Part 2. Relationships with Family and Friends

For the next questions we are interested in how people close to you respond to you when you are in need of support or reassurance. In answering the questions in the **first column**, please keep in mind a female family member who may be at risk for breast cancer **with whom you are closest**. Answer the questions in the **second column** keeping in mind **your spouse or intimate partner**. *If you do not have a spouse or intimate partner, please leave the second column blank.* For the **third column**, please keep in mind **another family member or friend to whom you are closest**.

		Female Family Member at Risk for Breast Cancer	Spouse/ Partner	Another Friend
1.	Was physically present when you needed him/her.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
2.	Told you what he/she did in a similar situation.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
3.	Did activities to help you get your mind off things.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
4.	Told you that the things you talk about are private—just between the two of you.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
5.	Suggested some action you should take.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
6.	Comforted you by showing you physical affection.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
7.	Listened to you talk about your private feelings.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
8.	Agreed that what you want to do is right.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
9.	Told you how he/she felt in a similar situation.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
10.	Let you know that he/she will always be around if you need assistance.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
11.	Gave you feedback on how you were doing without saying it was good or bad.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
12.	Pitched in and helped you do things that needed to get done.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
13.	Intruded into your personal feelings and concerns.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No

		Female Family Member at Risk for Breast Cancer		Spouse/ Partner		Another Friend	
14.	Gave you unsolicited advice.	☐ Yes	☐ No	☐ Yes	☐ No	☐ Yes	☐ No
15.	Attempted to make unwanted contact.	☐ Yes	☐ No	☐ Yes	☐ No	☐ Yes	☐ No
16.	Discouraged you from discussing your feelings and concerns.	☐ Yes	☐ No	☐ Yes	☐ No	☐ Yes	☐ No
17.	Minimized your worries or concerns.	☐ Yes	☐ No	☐ Yes	☐ No	☐ Yes	☐ No
18.	Rejected you for displaying emotional upset.	☐ Yes	☐ No	☐ Yes	☐ No	☐ Yes	☐ No
19.	Insisted that you remain upbeat and optimistic.	☐ Yes	☐ No	☐ Yes	☐ No	☐ Yes	☐ No
20.	Let you down when you were counting on him/her.	☐ Yes	☐ No	☐ Yes	☐ No	☐ Yes	☐ No

Please indicate the extent to which each of the following items describes your current family.

		Strongly Agree				Strongly Disagree
a.	Planning family activities is difficult because we misunderstand each other.	1	2	3	4	5
b.	In times of crisis we can turn to each other for support.	1	2	3	4	5
c.	We cannot talk to each other about the sadness we feel.	1	2	3	4	5
d.	Individuals are accepted for what they are.	1	2	3	4	5
e.	We avoid discussing our fears and concerns.	1	2	3	4	5
f.	We can express feelings to each other.	1	2	3	4	5
g.	There are lots of bad feelings in the family.	1	2	3	4	5
h.	We feel accepted for what we are.	1	2	3	4	5
i.	Making decisions is a problem for our family.	1	2	3	4	5
j.	We are able to make decisions about how to solve problems.	1	2	3	4	5
k.	We don't get along well together.	1	2	3	4	5
l.	We confide in each other.	1	2	3	4	5

2

Part 3. Coping

The next pages contain descriptions of situations you actually may have found yourself in or you can imagine to find yourself in. Each situation is followed by several statements about thoughts, concerns and action tendencies people may have in such a situation. Please try to imagine that you are in the situation described and indicate for **each** statement to what degree it is applicable to you. There are no right or wrong answers.

Please indicate for each statement below to what degree it is applicable to you, by circling your answer.

1 = not at all applicable to me
2 = not very much applicable to me
3 = a tiny bit applicable to me
4 = rather applicable to me
5 = strongly applicable to me

1. Imagine you have been suffering from headaches and dizziness for some period of time. You visit your doctor. He or she tells you things don't look good and refers you to a specialist for a rather trying medical examination.

a. I plan to ask the specialist as many questions as possible	1	2	3	4	5
b. I tell myself things will turn out to be alright	1	2	3	4	5
c. I plan to get a second opinion first	1	2	3	4	5
d. I plan to start reading about headaches and dizziness	1	2	3	4	5
e. For the time being I try not to think of unpleasant outcomes	1	2	3	4	5
f. I am not going to worry: such an examination is less worse than suffering from headaches all the time	1	2	3	4	5

2. Imagine that you work hard and you have become overweight. Your doctor has told you several times already that this is unwise. During a visit your doctor detects hypertension (high blood pressure).

a. I look on the blood pressure measure too in order to ensure that the doctor is not mistaken	1	2	3	4	5
b. I take things rather easy	1	2	3	4	5
c. I decide to live on as normal	1	2	3	4	5
d. I ask the doctor extensively about the risks and consequences involved	1	2	3	4	5
e. I tell myself 'some ailments are worse than this one'	1	2	3	4	5
f. I plan to start reading a lot about hypertension	1	2	3	4	5

3

Please indicate for each statement below to what degree it is applicable to you, by circling your answer.

1 = not at all applicable to me
2 = not very much applicable to me
3 = a tiny bit applicable to me
4 = rather applicable to me
5 = strongly applicable to me

3. Imagine you have heart complaints. Your specialist advises an operation. The specialist tells you that you will have to wait four months for the operation, and that it is not certain whether the operation will help your condition.

a. I believe that, in my case, the operation
    will help my condition   1   2   3   4   5

b. I decide to learn all that is known
    about heart surgery   1   2   3   4   5

c. I decide to undertake as many pleasant and useful
    activities as possible for the next few months   1   2   3   4   5

d. I am going to find out whether there is a chance that
    the operation will make things worse   1   2   3   4   5

e. I decide to contact other patients with the same
    medical problem, for information   1   2   3   4   5

f. I tell myself 'things will turn out to be alright'   1   2   3   4   5

4. Imagine that you visit your doctor, thinking you have minor bowel problems. The doctor diagnoses an acute appendicitis and tells you that you have to have an operation in the hospital as soon as possible.

a. I tell the doctor that I want to know precisely
    what he or she is going to do with me   1   2   3   4   5

b. I decide to relax now in the face
    of what is coming soon   1   2   3   4   5

c. I think about what can go wrong   1   2   3   4   5

d. I take things easy   1   2   3   4   5

e. I tell myself 'things will turn out to be alright'   1   2   3   4   5

f. I immediately try to call somebody who may
    inform me a bit about this operation   1   2   3   4   5

Part 4. Quality of Life

Below is a list of statements that other people with your illness have said are important. **By circling one number per line, please indicate how true each statement has been for you during the <u>past 7 days</u>.**

PHYSICAL WELL-BEING	Not at all	A little Bit	Some-what	Quite a bit	Very much
I lack energy.	0	1	2	3	4
I have nausea.	0	1	2	3	4
Because of my physical condition, I have trouble meeting the needs of my family.	0	1	2	3	4
I have pain.	0	1	2	3	4
I am bothered by side-effects of treatment.	0	1	2	3	4
I feel ill.	0	1	2	3	4
I am forced to spend time in bed.	0	1	2	3	4

SOCIAL/FAMILY WELL-BEING	Not at all	A little Bit	Some-what	Quite a bit	Very much
I feel close to my friends.	0	1	2	3	4
I get emotional support from my family.	0	1	2	3	4
I get support from my friends.	0	1	2	3	4
My family has accepted my illness.	0	1	2	3	4
I am satisfied with family communication about my illness.	0	1	2	3	4
I feel close to my partner (or the person who is my main support).	0	1	2	3	4
Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please check this box _ and go on to the next section.					
I am satisfied with my sex life.	0	1	2	3	4

EMOTIONAL WELL-BEING	Not at all	A little Bit	Some-what	Quite a bit	Very much
I feel sad.	0	1	2	3	4
I am satisfied with how I am coping with my illness.	0	1	2	3	4
I am losing hope in the fight against my illness.	0	1	2	3	4
I feel nervous.	0	1	2	3	4
I worry about dying.	0	1	2	3	4
I worry that my condition will get worse.	0	1	2	3	4

FUNCTIONAL WELL-BEING	Not at all	A little Bit	Some-what	Quite a bit	Very much
I am able to work (including work at home).	0	1	2	3	4
My work (including work at home) is fulfilling.	0	1	2	3	4
I am able to enjoy life.	0	1	2	3	4
I have accepted my illness.	0	1	2	3	4
I am sleeping well.	0	1	2	3	4
I am enjoying the things I usually do for fun.	0	1	2	3	4
I am content with my quality of life right now.	0	1	2	3	4

ADDITIONAL CONCERNS	Not at all	A little Bit	Some-what	Quite a bit	Very much
I have been short of breath.	0	1	2	3	4
I am self-conscious about the way I dress.	0	1	2	3	4
One or both of my arms are swollen or tender.	0	1	2	3	4
I feel sexually attractive.	0	1	2	3	4
I am bothered by hair loss.	0	1	2	3	4
I worry that other members of my family might someday get the same illness I have.	0	1	2	3	4
I worry about the effect of stress on my illness.	0	1	2	3	4
I am bothered by a change in weight.	0	1	2	3	4
I am able to feel like a woman.	0	1	2	3	4

Part 5. Understanding Spouse or Partner Experiences of Genetic Testing

We would like to understand your spouse's/partner's experience of genetic testing. Please check your preference about contacting your spouse/partner. If you give your permission for us to send your spouse/partner a questionnaire, please check the corresponding box below and provide his or her name and address.

❒ I give my permission to contact the following family member.	Name:_____ Address:_____ _____ City State Zip
❒ I do not give my permission to contact my spouse. ❒ I do not have a spouse or partner.	

THANK YOU FOR COMPLETING THIS SURVEY.

Social Relationships Supplemental Survey (U & M)

Part 1. General Information

1. If you **are** currently married, what was the date of your current marriage?
   Month _____ Year _____

2. Is this your first marriage?   (1) ☐ Yes   (5) ☐ No

3. How many children do you have? _____

   a. Number of children living at home _____

   b. Number who are under age 6 _____

4. Are you currently working for pay outside the home?   (1) ☐ Yes   (5) ☐ No

   a. If **yes**, about how many hours per week are you working for pay?

Less than 10	10-20	21-30	31-40	41 or more
☐	☐	☐	☐	☐

Part 2. Relationships with Family and Friends

For the next questions we are interested in how people close to you respond to you when you are in need of support or reassurance. In answering the questions in the **first column**, please keep in mind a female family member who may be at risk for breast cancer **with whom you are closest**. Answer the questions in the **second column** keeping in mind **your spouse or intimate partner**. *If you do not have a spouse or intimate partner, please leave the second column blank.* For the **third column**, please keep in mind **another family member or friend to whom you are closest**.

		Female Family Member at Risk for Breast Cancer	Spouse/ Partner	Another Friend
1.	Was physically present when you needed him/her.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
2.	Told you what he/she did in a similar situation.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
3.	Did activities to help you get your mind off things.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
4.	Told you that the things you talk about are private—just between the two of you.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
5.	Suggested some action you should take.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
6.	Comforted you by showing you physical affection.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
7.	Listened to you talk about your private feelings.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
8.	Agreed that what you want to do is right.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
9.	Told you how he/she felt in a similar situation.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
10.	Let you know that he/she will always be around if you need assistance.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
11.	Gave you feedback on how you were doing without saying it was good or bad.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
12.	Pitched in and helped you do things that needed to get done.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
13.	Intruded into your personal feelings and concerns.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No

		Female Family Member at Risk for Breast Cancer		Spouse/ Partner		Another Friend	
14.	Gave you unsolicited advice.	❏ Yes	❏ No	❏ Yes	❏ No	❏ Yes	❏ No
15.	Attempted to make unwanted contact.	❏ Yes	❏ No	❏ Yes	❏ No	❏ Yes	❏ No
16.	Discouraged you from discussing your feelings and concerns.	❏ Yes	❏ No	❏ Yes	❏ No	❏ Yes	❏ No
17.	Minimized your worries or concerns.	❏ Yes	❏ No	❏ Yes	❏ No	❏ Yes	❏ No
18.	Rejected you for displaying emotional upset.	❏ Yes	❏ No	❏ Yes	❏ No	❏ Yes	❏ No
19.	Insisted that you remain upbeat and optimistic.	❏ Yes	❏ No	❏ Yes	❏ No	❏ Yes	❏ No
20.	Let you down when you were counting on him/her.	❏ Yes	❏ No	❏ Yes	❏ No	❏ Yes	❏ No

Please indicate the extent to which each of the following items describes your current family.

		Strongly Disagree				Strongly Agree
a.	Planning family activities is difficult because we misunderstand each other.	1	2	3	4	5
b.	In times of crisis we can turn to each other for support.	1	2	3	4	5
c.	We cannot talk to each other about the sadness we feel.	1	2	3	4	5
d.	Individuals are accepted for what they are.	1	2	3	4	5
e.	We avoid discussing our fears and concerns.	1	2	3	4	5
f.	We can express feelings to each other.	1	2	3	4	5
g.	There are lots of bad feelings in the family.	1	2	3	4	5
h.	We feel accepted for what we are.	1	2	3	4	5
i.	Making decisions is a problem for our family.	1	2	3	4	5
j.	We are able to make decisions about how to solve problems.	1	2	3	4	5
k.	We don't get along well together.	1	2	3	4	5
l.	We confide in each other.	1	2	3	4	5

2

Part 3. Coping

The next pages contain descriptions of situations you actually may have found yourself in or you can imagine to find yourself in. Each situation is followed by several statements about thoughts, concerns and action tendencies people may have in such a situation. Please try to imagine that you are in the situation described and indicate for **each** statement to what degree it is applicable to you. There are no right or wrong answers. Please indicate for each statement below to what degree it is applicable to you, by circling your answer.

1 = not at all applicable to me
2 = not very much applicable to me
3 = a tiny bit applicable to me
4 = rather applicable to me
5 = strongly applicable to me

1. Imagine you have been suffering from headaches and dizziness for some period of time. You visit your doctor. He or she tells you things don't look good and refers you to a specialist for a rather trying medical examination.

a. I plan to ask the specialist as many questions
as possible   1   2   3   4   5

b. I tell myself things will turn out to be alright   1   2   3   4   5

c. I plan to get a second opinion first   1   2   3   4   5

d. I plan to start reading about headaches and
dizziness   1   2   3   4   5

e. For the time being I try not to think of unpleasant
outcomes   1   2   3   4   5

f. I am not going to worry: such an examination is less
worse than suffering from headaches all the time   1   2   3   4   5

2. Imagine that you work hard and you have become overweight. Your doctor has told you several times already that this is unwise. During a visit your doctor detects hypertension (high blood pressure).

a.   I look on the blood pressure measure too in order to
ensure that the doctor is not mistaken   1   2   3   4   5

b.   I take things rather easy   1   2   3   4   5

c.   I decide to live on as normal   1   2   3   4   5

d.   I ask the doctor extensively about the risks and
consequences involved   1   2   3   4   5

e.   I tell myself 'some ailments are worse than this one'   1   2   3   4   5

f.   I plan to start reading a lot about hypertension   1   2   3   4   5

1 = not at all applicable to me
2 = not very much applicable to me
3 = a tiny bit applicable to me
4 = rather applicable to me
5 = strongly applicable to me

3. Imagine you have heart complaints. Your specialist advises an operation. The specialist tells you that you will have to wait four months for the operation, and that it is not certain whether the operation will help your condition.

a. I believe that, in my case, the operation
   will help my condition   1   2   3   4   5

b. I decide to learn all that is known
   about heart surgery   1   2   3   4   5

c. I decide to undertake as many pleasant and useful
   activities as possible for the next few months   1   2   3   4   5

d. I am going to find out whether there is a chance that
   the operation will make things worse   1   2   3   4   5

e. I decide to contact other patients with the same
   medical problem, for information   1   2   3   4   5

f. I tell myself 'things will turn out to be alright'   1   2   3   4   5

4. Imagine that you visit your doctor, thinking you have minor bowel problems. The doctor diagnoses an acute appendicitis and tells you that you have to have an operation in the hospital as soon as possible.

a. I tell the doctor that I want to know precisely
   what he or she is going to do with me   1   2   3   4   5

b. I decide to relax now in the face
   of what is coming soon   1   2   3   4   5

c. I think about what can go wrong   1   2   3   4   5

d. I take things easy   1   2   3   4   5

e. I tell myself 'things will turn out to be alright'   1   2   3   4   5

f. I immediately try to call somebody who may
   inform me a bit about this operation   1   2   3   4   5

4

Part 4. Understanding Spouse or Partner Experiences of Genetic Testing

We would like to understand your spouse's/partner's experience of genetic testing. Please check your preference about contacting your spouse/partner. If you give your permission for us to send your spouse/partner a questionnaire, please check the corresponding box below and provide his or her name and address.

❏ I give my permission to contact the following family member.	Name:_____ Address:_____ _____ City State Zip
❏ I do not give my permission to contact my spouse. ❏ I do not have a spouse or partner.	

THANK YOU FOR COMPLETING THIS SURVEY.

5

B.III. Pre-Results Questionnaires

Pre-Results Assessment – U
Pre-Results Questionnaire – A

TODAY'S DATE _____   ID _____

You may notice that some of these questions were asked in previous questionnaires, but many of the questions are new. We are asking them again because we are interested in feelings and attitudes which may change over time. THANK YOU VERY MUCH!

GENETIC TESTING-SECTION 1

1. Have you met with anyone to have genetic counseling?   B24.
    (1) ☐ Yes   (5) ☐ No

2. Has any member of your family met with someone to have genetic counseling ?   B25.
    (1) ☐ Yes   (5) ☐ No

3. As the opportunity to get testing has approached, has your interest in getting results changed?   B74.

Decreased Very Much 1	Decreased Slightly 2	No Change 3	Increased Slightly 4	Increased Very Much 5

4. At this time, what is your decision regarding receiving your genetic results?   B112.
    (1) ☐   I will probably or definitely receive my results now, as soon as they are offered.
            (Skip to Question 5)

    (3) ☐   I do not intend to receive my results now, but may do so later. (Skip to Question 6)

    (5) ☐   I do not intend to receive my results now or in the future. (Skip to Question 7)

5. If you will probably or definitely obtain your results _now_ , as soon as they are being offered
    to you, what are your reasons for doing so?   B113.
    (Please check all that apply **and then circle the number of the statement
    which indicates your most important reason for receiving your results** _now_).
    (1) ☐   I just want to know whether I have the gene. I am happier knowing.
    (2) ☐   In order to decide whether to get prophylactic surgery.
    (3) ☐   To assist me in other medical decisions.
    (4) ☐   To make decisions about family planning.
    (5) ☐   To make decisions about financial planning and insurance.
    (6) ☐   To make lifestyle and other non-medical decisions.
    (7) ☐   To find out the risk that may be transmitted to my children.
    (8) ☐   Family members want me to get testing.
    (9) ☐   I want to help other family members by providing them with my results.
    (10) ☐   Other (please describe) _____

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6. If you do **_not_** intend to obtain your results **_now_**, but may do so **_later_**, please indicate your   B114.
reasons.
(Please check all that apply <u>and</u> then circle the number of the statement which indicates your most important reason for delaying receiving your results).

- (1) ☐   I am happier not knowing.
- (2) ☐   There are no decisions I need to make at this time for which knowledge of my results would be useful.
- (3) ☐   It would be too upsetting to learn that I have a mutation associated with increased risk of cancer.
- (4) ☐   Knowing that I have a mutation would interfere with my life as it is now.
- (5) ☐   There would not be much I could now do to reduce my risk of cancer if I found out I had a mutation.
- (6) ☐   I am too worried about the effects of knowing my results on women in my family.
- (7) ☐   Family members do not want me to get testing.
- (8) ☐   Family members want me to get testing, but I am not ready to do so.
- (9) ☐   I want to wait until there is less risk to insurance coverage.
- (10) ☐   I want to wait until there is less risk to employment.
- (11) ☐   I am either too young or too old to benefit from knowing if I have a mutation.
- (12) ☐   I want to wait until more is known about breast/ovarian cancer genes and what can be done to reduce a women's risk of cancer.
- (13) ☐   I simply am not ready to make up my mind at this time.
- (14) ☐   Other (please describe) _____

7. If you do **_not_** intend to obtain your results **_now or in the future_**, please indicate your reasons.   B115.
(Please check all that apply <u>and</u> then circle the number of the statement which indicates your most important reason for not receiving your results).

- (1) ☐   I am happier not knowing.
- (2) ☐   There are no decisions I need to make for which knowledge of my results would be useful.
- (3) ☐   It would be too upsetting to learn that I have a mutation associated with increased risk of cancer.
- (4) ☐   Knowing that I have a mutation would interfere with my life.
- (5) ☐   There would not be much I could do to reduce my risk of cancer if I found out I had a mutation.
- (6) ☐   I am too worried about the effects of knowing my results on women in my family.
- (7) ☐   Family members do not want me to get testing.
- (8) ☐   Risk to my insurance coverage.
- (9) ☐   Risk to my employment.
- (10) ☐   I am either too young or too old to benefit from knowing if I have a mutation.
- (11) ☐   I do not believe in obtaining personal genetic information.
- (12) ☐   Other (please describe) _____

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PERSONAL ATTITUDES SECTION

1. For each of these statements, please indicate the extent to which you agree or disagree by circling the appropriate number. There are no right or wrong answers. We are only interested in your opinions.

		Strongly Disagree				Strongly Agree	
a.	If you don't have your health, you don't have anything.	1	2	3	4	5	L5a.
b.	There are many things I care about more than my health.	1	2	3	4	5	L5b.
c.	Good health is of only minor importance in a happy life.	1	2	3	4	5	L5c.
d.	There is nothing more important than good health.	1	2	3	4	5	L5d.
e.	In uncertain times, I usually expect the best.	1	2	3	4	5	E1.
f.	It's easy for me to relax.	1	2	3	4	5	E2.
g.	If something can go wrong for me, it will.	1	2	3	4	5	E3.
h.	I always look on the bright side of things.	1	2	3	4	5	E4.
i.	I'm always optimistic about my future.	1	2	3	4	5	E5.
j.	I enjoy my friends a lot.	1	2	3	4	5	E6.
k.	It's important for me to keep busy.	1	2	3	4	5	E7.
l.	I hardly ever expect things to go my way.	1	2	3	4	5	E8.
m.	Things never work out the way I want them to.	1	2	3	4	5	E9.
n.	I don't get upset too easily.	1	2	3	4	5	E10.
o.	I'm a believer in the idea that "every cloud has a silver lining."	1	2	3	4	5	E11.
p.	I rarely count on good things happening to me.	1	2	3	4	5	E12.

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GENETIC TESTING-SECTION 2

Using the following scales, please circle your response for each question.

		Not At All				Very Much	Not Appli-cable	
1.	How distressing is it for you to know that you may be at increased risk for breast or ovarian cancer because of your family history?	1	2	3	4	5	-8	B66.
2.	How distressing is it to be given the opportunity to be tested for an altered BRCA-1/BRCA2, the altered genes associated with increased risk for breast and ovarian cancer?	1	2	3	4	5	-8	B67.
3.	How distressed do you expect to be if you get tested for an altered BRCA-1/BRCA2 gene (just before you receive results)?	1	2	3	4	5	-8	B68.
4.	How distressed **would** you be if you took the test and found that you **had** an altered BRCA-1/ BRCA2 gene?	1	2	3	4	5	-8	B69.
5.	How distressed **would** you be if you took the test and found that you **did not have** an altered BRCA1/ BRCA2 gene?	1	2	3	4	5	-8	B70.
6.	Overall, to what extent do you welcome the opportunity to be tested for an altered BRCA-1/ BRCA2 gene?	1	2	3	4	5	-8	B71.

		Not At All			All The Time		
7.	How often do you worry about developing breast or ovarian cancer?	1	2	3	4	5	B27.
8.	To what extent do these worries interfere with your every day life?	1	2	3	4	5	B28.
9.	How often do you worry about having an altered gene which conveys heightened risk for breast and ovarian cancer ?	1	2	3	4	5	B29.
10.	To what extent do these worries you have about having this altered gene interfere with your every day life?	1	2	3	4	5	B30.

11. When was the last time you had a mammogram?   B32.

(Month/Year) _____   ☐(-8) Does not apply because of surgery.

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12.   How many times have you conducted a breast self-examination in the past six months?   **B33.**

_____ times   ☐(-8) Does not apply because of surgery.

13.   How confident are you that you will perform breast self examination (BSE) ---

13a.   --as **frequently** as needed? (-8)☐ Does Not Apply Because of Surgery.   **B34a.**

Not at All   Very Much So
   1   2   3   4   5   6   7

13b.   --as **carefully and competently** as needed?   **B34b.**

(-8) ☐ Does Not Apply Because of Surgery

Not at All   Very Much So
   1   2   3   4   5   6   7

For each of the following areas of your life, we ask you to make **two** ratings. First, indicate how much these decisions have been affected by _**being at risk for breast or ovarian cancer**_ (based on your family history). Second, how much these decisions would be affected by _**the results of genetic testing**_ ?

1	2	3	4	5
Not at all affected			**Very much affected**	

		Have been affected by being at risk for breast or ovarian cancer					_Would be affected by the results of genetic testing_					
14.	Decisions about having children	1	2	3	4	5	1	2	3	4	5	B35a B35b
15.	Decisions about form of birth control	1	2	3	4	5	1	2	3	4	5	B36a B36b
16.	Decisions about which steps to take to prevent the occurrence of breast or ovarian cancer	1	2	3	4	5	1	2	3	4	5	B37a B37b
17.	Decisions about work and career	1	2	3	4	5	1	2	3	4	5	B38a B38b
18.	Decisions about savings and financial planning	1	2	3	4	5	1	2	3	4	5	B39a B39b
19.	Decisions about plans for the future	1	2	3	4	5	1	2	3	4	5	B40a B40b

20.   **Answer the following question only if you have daughters.**

☐ Does Not Apply (Skip to the next question, 22)   **B41.**

1	2	3	4	5
Not at all affected			**Very much affected**	

		Have been affected by being at high risk for breast or ovarian cancer					*Would be affected by the results of genetic testing*					
a-b.	Plans for your daughter's future	1	2	3	4	5	1	2	3	4	5	**B42 a/b**

21. Do you feel you have enough information about breast or ovarian cancer to make any decisions that might be necessary?

Not At All				Very Much		
1	2	3	4	5	6	7

B43.

22. Do you feel you are adequately informed about the benefits and drawbacks of genetic testing for risk of breast and ovarian cancer?

Not At All				Very Much		
1	2	3	4	5	6	7

B44.

23. Do you feel you are adequately informed about what you could do to reduce your risk of breast and ovarian cancer if you had an altered BRCA1/BRCA2 gene?

Not At All				Very Much		
1	2	3	4	5	6	7

B45.

24. Do you feel you are adequately informed about the benefits and drawbacks of each option available to women who have an altered BRCA1/BRCA2 gene?

Not At All				Very Much		
1	2	3	4	5	6	7

B46.

25. Do you feel you are adequately informed about what it would mean for your children if you had an altered BRCA1/BRCA2 gene?

Not At All				Very Much		
1	2	3	4	5	6	7

B47.

26. How confident are you that you will make the best decision in deciding whether to be tested for BRCA1/BRCA2?

Not At All				Very Much		
1	2	3	4	5	6	7

B48a.

27. How confident are you that you would cope effectively with a finding that you had an altered BRCA1/BRCA2 gene?

Not At All				Very Much		
1	2	3	4	5	6	7

B48b.

28. How confident are you that you would make the best decision concerning your options if you were found to have an altered BRCA1/BRCA2 gene?

Not At All				Very Much		
1	2	3	4	5	6	7

B48c.

29. How confident are you that you would be able to follow through and cope effectively over the long haul if you were found to have an altered BRCA1/BRCA2 gene?

Not At All				Very Much		
1	2	3	4	5	6	7

B48d.

RELATIONSHIPS SECTION

1. Is there anyone in your life with whom you can share your most private feelings
    without holding back?   **C21.**

    (1) ☐ Yes   (5) ☐ No

2. If married, can you share your most private feelings with your spouse/partner without
    holding back?   **C21a.**

    (1) ☐ Yes   (5) ☐ No

3. If married, is there anyone besides your spouse/partner with whom you can share
    your most private feelings without holding back?   **C21b.**

    (1) ☐ Yes   (5) ☐ No

LIFE EVENTS SECTION

1. Have any of the following events happened to you in <u>the past six months</u>?   **D1(a-m)**
    (Please Check All That Apply)

a. ☐ You retired, were fired, or laid off from work.

b. ☐ You were unemployed and looking for work.

c. ☐ Your spouse retired, was fired, or laid off from work.

d. ☐ Your spouse was unemployed and looking for work.

e. ☐ You had problems with the police or court.

f. ☐ You got into serious financial difficulties.

g. ☐ A close family member was seriously ill or injured.

h. ☐ You had a marital separation or divorce.

i. ☐ You had serious troubles with relatives or close friends.

j. ☐ Your spouse had troubles or difficulties with relatives or close friends.

k. ☐ A close family member died.

l. ☐ A close friend or relative died.

m. ☐ You were seriously ill or injured.

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MARRIAGE SECTION

The following questions apply to persons who are <u>married or living with a partner</u>. *If you are not married or living with a partner, please check the box and skip to page 11, Mood Section.*

Not married or living with a partner ☐   **Ea.**

Most people have disagreements in their relationships. Please indicate by circling the number that represents the extent of agreement or disagreement experienced between you and your spouse/partner **DURING THE PAST MONTH**.

		Always Disagree	*Almost Always Disagree*	*Fre-quently Disagree*	*Occa-sionally Disagree*	*Almost Always Agree*	*Always Agree*	
1.	Religious matters	1	2	3	4	5	6	**H3.**
2.	Demonstration of affection	1	2	3	4	5	6	**H4.**
3.	Sex relations	1	2	3	4	5	6	**H6.**
4.	Conventionality (correct or proper behavior)	1	2	3	4	5	6	**H7.**
5.	Making major decisions	1	2	3	4	5	6	**H12.**
6.	Career decisions	1	2	3	4	5	6	**H15.**

		Never	*Rarely*	*Occa-sionally*	*More often than most*	*Most of the time*	*All of the time*	
7.	How often do you discuss or have you considered divorce, separation, or terminating your relationship?	1	2	3	4	5	6	**H16.**
8.	Do you ever regret that you married (or lived together)?	1	2	3	4	5	6	**H20.**
9.	How often do you and your partner quarrel?	1	2	3	4	5	6	**H21.**
10.	How often do you and your spouse/partner "get on each other's nerves?"	1	2	3	4	5	6	**H22.**

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		None of Them	Very Few of Them	Some of Them	Most of Them	All of Them	
11.	To what extent do you and your spouse/partner share interests together?	1	2	3	4	5	H24.

How often would you say the following events occur between you and your spouse/partner?

		Never	Less than once a month	About twice a month	About twice a week	Once a day	More Often	
12.	Have a stimulating exchange of ideas	1	2	3	4	5	6	H25.
13.	Calmly discuss something	1	2	3	4	5	6	H27.
14.	Work together on a project	1	2	3	4	5	6	H28.

15. Considering **only the positive feelings** you have towards your spouse/partner, and **ignoring the negative ones**, please rate how positive these feelings are: ·H33.

Not At All Positive								Extremely Positive	
1	2	3	4	5	6	7	8	9	10

16. Considering **only the negative feelings** you have towards your spouse/partner, and **ignoring the positive ones**, please rate how negative these feelings are: H34.

Not At All Negative								Extremely Negative	
1	2	3	4	5	6	7	8	9	10

17. The following questions concern your spouse/partner's involvement in your health care.

		Never				Very Often	
a.	How often does your spouse/partner go with you to your appointments with doctors?	1	2	3	4	5	H35a.
b.	How often does your spouse/partner talk with your doctor or other medical personnel about your risk for breast or ovarian cancer?	1	2	3	4	5	H35b.
c.	How often does your spouse/partner keep track of what you need to do about your risk for breast or ovarian cancer?	1	2	3	4	5	H35c.
d.	How often does your spouse/partner change their activities to assist you in your health care?	1	2	3	4	5	H35d.

18. Has your spouse/partner attended individual, family or group sessions to become informed about your risk for breast or ovarian cancer and what can be done?　　　**H36.**

　　　(1) ☐ Yes　　　(5) ☐ No

19. How much contact has your spouse/partner had with medical personnel concerning your risk for breast or ovarian cancer?　　　**H37.**

```
Very Little
 or None                                        A lot
   1       2      3      4      5      6        7
```

20. Do you feel your spouse/partner is adequately informed concerning your risk for breast or ovarian cancer and what can be done about it?　　　**H38.**

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Not at All                                  Very Much
   1       2      3      4      5      6        7
```

21. To what extent are you satisfied with your spouse/partner's involvement in your health care?　　　**H39.**

```
Not at All                                  Very Much
   1       2      3      4      5      6        7
```

MOOD SECTION

1. In **the past year**, have you had two weeks or more when nearly every day you felt sad, blue, or depressed <u>or</u> in which you lost all interest in things like work or hobbies or things you usually liked to do for fun?　　　**I12.**

　　　(1) ☐ Yes　　　(5) ☐ No (Skip to Question 2)

　1a.　During this period, did your work or relationships suffer?　　　**I12a.**
　　　(1) ☐ Yes　　　(5) ☐ No

　1b.　During this period, did you get counseling or psychotherapy?　　　**I12b.**
　　　(1) ☐ Yes　　　(5) ☐ No

　1c.　During this period, did you get medication for this condition?　　　**I12c.**
　　　(1) ☐ Yes　　　(5) ☐ No

2. Are you **currently** receiving counseling, psychotherapy, or medication for depression or emotional problems?　　　**I13.**

　　　(1) ☐ Yes　　　(5) ☐ No

SYMPTOMS OF STRAIN SECTION

LISTED BELOW ARE SOME SYMPTOMS OF STRAIN THAT PEOPLE SOMETIMES HAVE. *Please Read Each One Carefully And Check The Answer Which Best Reflects How Much That Symptom Has Bothered You During the __Past Three Months__.*

		Not at all	*A little*	*Quite a bit*	*Extremely*	
1.	Suddenly scared for no reason	1	2	3	4	K1.
2.	Feeling fearful	1	2	3	4	K2.
3.	Faintness, dizziness, or weakness	1	2	3	4	K3.
4.	Nervousness or shakiness inside	1	2	3	4	K4.
5.	Heart pounding or racing	1	2	3	4	K5.
6.	Trembling	1	2	3	4	K6.
7.	Feeling tense or keyed up	1	2	3	4	K7.
8.	Headaches	1	2	3	4	K8.
9.	Spells of terror or panic	1	2	3	4	K9.
10.	Feeling restless, can't sit still	1	2	3	4	K10.
11.	Feeling low in energy--slowed down	1	2	3	4	K11.
12.	Blaming yourself for things	1	2	3	4	K12.
13.	Crying easily	1	2	3	4	K13.
14.	Loss of sexual interest or pleasure	1	2	3	4	K14.
15.	Poor appetite	1	2	3	4	K15.
16.	Difficulty falling asleep, staying asleep	1	2	3	4	K16.
17.	Feeling hopeless about the future	1	2	3	4	K17.
18.	Feeling blue	1	2	3	4	K18.
19.	Feeling lonely	1	2	3	4	K19.
20.	Feeling trapped or caught	1	2	3	4	K20.
21.	Worrying too much about things	1	2	3	4	K21.
22.	Feeling no interest in things	1	2	3	4	K22.
23.	Thoughts of ending your life	1	2	3	4	K23.
24.	Feeling everything is an effort	1	2	3	4	K24.

| 25. | Feelings of worthlessness | 1 | 2 | 3 | 4 | | K25. |

COPING SECTION

1. Sometimes people can find unexpected benefits in difficulties. We are interested in the ways in which you might have made positive use of your risk for breast or ovarian cancer. For each of the statements below, indicate the degree to which your life is affected <u>positively</u> by your risk of breast or ovarian cancer.

		Not At All	A Very Small Degree	A Small Degree	A Moderate Degree	A Great Degree	A Very Great Degree	
a.	My priorities about what is important in life.	1	2	3	4	5	6	L6a.
b.	I'm more likely to try to change things which need changing.	1	2	3	4	5	6	L6b.
c.	An appreciation for the value of my own life.	1	2	3	4	5	6	L6c.
d.	A feeling of self-reliance.	1	2	3	4	5	6	L6d.
e.	A better understanding of spiritual matters.	1	2	3	4	5	6	L6e.
f.	Knowing that I can count on people in times of troubles.	1	2	3	4	5	6	L6f.
g.	A sense of closeness with others.	1	2	3	4	5	6	L6g.
h.	Knowing I can handle difficulties.	1	2	3	4	5	6	L6h.
i.	A willingness to express my emotions.	1	2	3	4	5	6	L6i.
j.	Being able to accept the way things work out.	1	2	3	4	5	6	L6j.
k.	Appreciating each day.	1	2	3	4	5	6	L6k.
l.	Having compassion for others.	1	2	3	4	5	6	L6l.
m.	I'm able to do better things with my life.	1	2	3	4	5	6	L6m.
n.	New opportunities are available which wouldn't have been otherwise.	1	2	3	4	5	6	L6n.

2. This set of questions deals with ways you've been coping with the stress in your life that comes with being at risk for breast or ovarian cancer. There are many ways people try to deal with problems. Obviously, different people deal with things in different ways, but we are interested in how you've tried to deal with it. Each item says something about a particular way of coping. We want to know *to what extent* you've been doing what the item says, how *much* or how *frequently*. Don't answer on the basis of whether it seems to be working but just whether or not you're doing it. Use these response choices below and try not to let one answer influence another. Please make your answers as true FOR YOU as you can..

		I haven't been doing this at all 1	I've been doing this a little bit 2	I've been doing this some 3	I've been doing this a lot 4	
a.	I've been turning to work or other activities to take my mind off things.	1	2	3	4	L7a.
b.	I've been concentrating my efforts on doing something about my situation.	1	2	3	4	L7b.
c.	I've been saying to myself "this isn't possible."	1	2	3	4	L7c.
d.	I've been using alcohol or other drugs to make myself feel better.	1	2	3	4	L7d.
e.	I've been getting emotional support from others.	1	2	3	4	L7e.
f.	I've been giving up trying to deal with it.	1	2	3	4	L7f.
g.	I've been taking action to try to make the situation better.	1	2	3	4	L7g.
h.	I've been refusing to believe that it is possible that I have an altered gene.	1	2	3	4	L7h.
i.	I've been saying things to let my unpleasant feelings escape.	1	2	3	4	L7i.
j.	I've been using alcohol or other drugs to help me get through it.	1	2	3	4	L7j.
k.	I've been trying to see it in a different light, to make it seem more positive.	1	2	3	4	L7k.
l.	I've been trying to come up with a strategy about what to do.	1	2	3	4	L7l.
m.	I've been getting comfort and understanding from someone.	1	2	3	4	L7m.

		I haven't been doing this at all 1	I've been doing this a little bit 2	I've been doing this some 3	I've been doing this a lot 4
n.	I've been giving up the attempt to cope.	1	2	3	4
o.	I've been accepting the possibility that I might have an altered gene.	1	2	3	4
p.	I've been expressing my negative feelings.	1	2	3	4
q.	I've been trying to find comfort in my religion or spiritual beliefs.	1	2	3	4
r.	I've been learning to live with the possibility that I might have the gene.	1	2	3	4
s.	I've been thinking hard about what steps to take.	1	2	3	4
t.	I've been praying or meditating.	1	2	3	4
u.	I've been making fun of the situation.	1	2	3	4

L7n.

L7o.

L7p.

L7q.

L7r.

L7s.

L7t.

L7u.

3. The following items are to be answered only by those women who are _married or living with a partner_.
   ☐ Not married or living with a partner
   (Skip to the last section on next page)

L8.

		I haven't been doing this at all 1	I've been doing this a little bit 2	I've been doing this some 3	I've been doing this a lot 4
a.	I've been denying or hiding my anger around my spouse/partner.	1	2	3	4
b.	I've been denying or hiding my worries around my spouse/partner.	1	2	3	4
c.	I've been avoiding talking about my problems around my spouse/partner.	1	2	3	4
d.	I've acted more positive around my spouse/partner than I feel.	1	2	3	4

L8a.

L8b.

L8c.

L8d.

15

BACKGROUND DATA SECTION

These are a few questions about your religious background that we forgot to ask on the original questionnaire.

1.   Religion: Catholic   (1) ☐   Protestant   (4) ☐   **A3.**
                                 Jewish   (2) ☐   Buddhist   (5) ☐
                                   Muslim   (3) ☐   Other   (6) ☐
                                                    None   (7) ☐

     1a.   How often do you attend religious services?   **A3a.**
                (1)   (5)
                ☐ Less Often Than Once a Month   ☐   A Few Times A Month or More

     1b.   How important are religious and spiritual beliefs in your life?   **A3b.**

           Not at All   Very Important
              1   2   3   4   5

Once again, We thank you for all of your valued participation in this study.

You may notice that some of these questions were asked in previous questionnaires, but many of the questions are new. We are asking them again because we are interested in feelings and attitudes which may change over time. THANK YOU VERY MUCH!

GENETIC TESTING-SECTION 1

1.   Have you met with anyone to have genetic counseling?   B24.
                (1) ☐ Yes   (5) ☐ No

2.   Has any member of your family met with someone to have genetic counseling ?   B25.
                (1) ☐ Yes   (5) ☐ No

3.   As the opportunity to get testing has approached, has your interest in getting results changed?   B74.

Decreased Very Much 1	Decreased Slightly 2	No Change 3	Increased Slightly 4	Increased Very Much 5

4.   At this time, what is your decision regarding receiving your genetic results?   B112.
        (1) ☐   I will probably or definitely receive my results now, as soon as they are offered. (Skip to Question 5)

        (3) ☐   I do not intend to receive my results now, but may do so later. (Skip to Question 6)

        (5) ☐   I do not intend to receive my results now or in the future. (Skip to Question 7)

5.   If you will probably or definitely obtain your results _now_ , as soon as they are being offered to you, what are your reasons for doing so?   B113.
    (Please check all that apply and then circle the number of the statement which indicates your most important reason for receiving your results _now_).
    (1) ☐   I just want to know whether I have the gene. I am happier knowing.
    (2) ☐   In order to decide whether to get prophylactic surgery.
    (3) ☐   To assist me in other medical decisions.
    (4) ☐   To make decisions about family planning.
    (5) ☐   To make decisions about financial planning and insurance.
    (6) ☐   To make lifestyle and other non-medical decisions.
    (7) ☐   To find out the risk that may be transmitted to my children.
    (8) ☐   Family members want me to get testing.
    (9) ☐   I want to help other family members by providing them with my results.
    (10) ☐   Other (please describe) _____

1

6. If you do *not* intend to obtain your results *now*, but may do so *later*, please indicate your   **B114.**
reasons.
(Please check all that apply <u>and</u> then circle the number of the statement which indicates your most important reason for delaying receiving your results).

- (1) ☐   I am happier not knowing.
- (2) ☐   There are no decisions I need to make at this time for which knowledge of my results would be useful.
- (3) ☐   It would be too upsetting to learn that I have a mutation associated with increased risk of cancer.
- (4) ☐   Knowing that I have a mutation would interfere with my life as it is now.
- (5) ☐   There would not be much I could now do to reduce my risk of cancer if I found out I had a mutation.
- (6) ☐   I am too worried about the effects of knowing my results on women in my family.
- (7) ☐   Family members do not want me to get testing.
- (8) ☐   Family members want me to get testing, but I am not ready to do so.
- (9) ☐   I want to wait until there is less risk to insurance coverage.
- (10) ☐   I want to wait until there is less risk to employment.
- (11) ☐   I am either too young or too old to benefit from knowing if I have a mutation.
- (12) ☐   I want to wait until more is known about breast/ovarian cancer genes and what can be done to reduce a women's risk of cancer.
- (13) ☐   I simply am not ready to make up my mind at this time.
- (14) ☐   Other (please describe) _____

7. If you do *not* intend to obtain your results *now or in the future*, please indicate your reasons.   **B115.**
(Please check all that apply <u>and</u> then circle the number of the statement which indicates your most important reason for not receiving your results).

- (1) ☐   I am happier not knowing.
- (2) ☐   There are no decisions I need to make for which knowledge of my results would be useful.
- (3) ☐   It would be too upsetting to learn that I have a mutation associated with increased risk of cancer.
- (4) ☐   Knowing that I have a mutation would interfere with my life.
- (5) ☐   There would not be much I could do to reduce my risk of cancer if I found out I had a mutation.
- (6) ☐   I am too worried about the effects of knowing my results on women in my family.
- (7) ☐   Family members do not want me to get testing.
- (8) ☐   Risk to my insurance coverage.
- (9) ☐   Risk to my employment.
- (10) ☐   I am either too young or too old to benefit from knowing if I have a mutation.
- (11) ☐   I do not believe in obtaining personal genetic information.
- (12) ☐   Other (please describe) _____

2

PERSONAL ATTITUDES SECTION

1. For each of these statements, please indicate the extent to which you agree or disagree by circling the appropriate number. There are no right or wrong answers. We are only interested in your opinions.

		Strongly Disagree				Strongly Agree	
a.	If you don't have your health, you don't have anything.	1	2	3	4	5	L5a.
b.	There are many things I care about more than my health.	1	2	3	4	5	L5b.
c.	Good health is of only minor importance in a happy life.	1	2	3	4	5	L5c.
d.	There is nothing more important than good health.	1	2	3	4	5	L5d.
e.	In uncertain times, I usually expect the best.	1	2	3	4	5	E1.
f.	It's easy for me to relax.	1	2	3	4	5	E2.
g.	If something can go wrong for me, it will.	1	2	3	4	5	E3.
h.	I always look on the bright side of things.	1	2	3	4	5	E4.
i.	I'm always optimistic about my future.	1	2	3	4	5	E5.
j.	I enjoy my friends a lot.	1	2	3	4	5	E6.
k.	It's important for me to keep busy.	1	2	3	4	5	E7.
l.	I hardly ever expect things to go my way.	1	2	3	4	5	E8.
m.	Things never work out the way I want them to.	1	2	3	4	5	E9.
n.	I don't get upset too easily.	1	2	3	4	5	E10.
o.	I'm a believer in the idea that "every cloud has a silver lining."	1	2	3	4	5	E11.
p.	I rarely count on good things happening to me.	1	2	3	4	5	E12.

GENETIC TESTING-SECTION 2

Using the following scales, please circle your response for each question.

		Not At All			Very Much		Not Appli-cable	
1.	How distressing is it for you to know that you may be at increased risk for recurrence of breast or ovarian cancer because of your family history?	1	2	3	4	5	-8	B66.
2.	How distressing is it to be given the opportunity to be tested for an altered BRCA1/BRCA2, the altered genes associated with increased risk for breast and ovarian cancer?	1	2	3	4	5	-8	B67.
3.	How distressed do you expect to be if you get tested for an altered BRCA1/BRCA2 gene (just before you receive results)?	1	2	3	4	5	-8	B68.
4.	How distressed **would** you be if you took the test and found that you **had** an altered BRCA1/ BRCA2 gene?	1	2	3	4	5	-8	B69.
5.	How distressed **would** you be if you took the test and found that you **did not have** an altered BRCA1/ BRCA2 gene?	1	2	3	4	5	-8	B70.
6.	Overall, to what extent do you welcome the opportunity to be tested for an altered BRCA1/ BRCA2 gene?	1	2	3	4	5	-8	B71.

		Not At All			All The Time		
7.	How often do you worry about again developing breast or ovarian cancer?	1	2	3	4	5	B27.
8.	To what extent do these worries interfere with your every day life?	1	2	3	4	5	B28.
9.	How often do you worry about having an altered gene which conveys heightened risk for breast and ovarian cancer ?	1	2	3	4	5	B29.
10.	To what extent do these worries you have about having this altered gene interfere with your every day life?	1	2	3	4	5	B30.

11. When was the last time you had a mammogram?   B32.

   (Month/Year) _____   ☐(-8) Does not apply because of surgery.

4

12. How many times have you conducted a breast self-examination in the past six months? **B33.**

_____ times   ☐ (-8) Does not apply because of surgery.

13. How confident are you that you will perform breast self examination (BSE) ---

   13a. --as **frequently** as needed? (-8) ☐ Does Not Apply Because of Surgery. **B34a.**

Not at All						Very Much So
1	2	3	4	5	6	7

   13b. --as **carefully and competently** as needed? **B34b.**

               (-8) ☐ Does Not Apply Because of Surgery

Not at All						Very Much So
1	2	3	4	5	6	7

For each of the following areas of your life, we ask you to make **two** ratings. First, indicate how much these decisions have been affected by _**being at increased risk for breast or ovarian cancer**_ (based on your family history). Second, how much these decisions would be affected by _**the results of genetic testing**_ ?

1	2	3	4	5
Not at all affected				Very much affected

		Have been affected by being at increased risk for breast or ovarian cancer					_Would be affected by the results of genetic testing_					
14.	Decisions about having children	1	2	3	4	5	1	2	3	4	5	B35a B35b
15.	Decisions about form of birth control	1	2	3	4	5	1	2	3	4	5	B36a B36b
16.	Decisions about which steps to take to prevent the recurrence of breast or ovarian cancer	1	2	3	4	5	1	2	3	4	5	B37a B37b
17.	Decisions about work and career	1	2	3	4	5	1	2	3	4	5	B38a B38b
18.	Decisions about savings and financial planning	1	2	3	4	5	1	2	3	4	5	B39a B39b
19.	Decisions about plans for the future	1	2	3	4	5	1	2	3	4	5	B40a B40b

20. **Answer the following question only if you have daughters.**

☐ Does Not Apply (Skip to the next question, 21)   B41.

1	2	3	4	5
Not at all affected			Very much affected	

		Have been affected by being at high risk for breast or ovarian cancer					Would be affected by the results of genetic testing					
a-b.	Plans for your daughter's future	1	2	3	4	5	1	2	3	4	5	B42 a/b

21. Do you feel you have enough information about breast or ovarian cancer to make any decisions that might be necessary?

Not At All				Very Much		
1	2	3	4	5	6	7

B43.

22. Do you feel you are adequately informed about the benefits and drawbacks of genetic testing for risk of breast and ovarian cancer?

Not At All				Very Much		
1	2	3	4	5	6	7

B44.

23. Do you feel you are adequately informed about what you could do to reduce your risk of recurrence of breast and ovarian cancer if you had an altered BRCA1/BRCA2 gene?

Not At All				Very Much		
1	2	3	4	5	6	7

B45.

24. Do you feel you are adequately informed about the benefits and drawbacks of each option available to women who have an altered BRCA1/BRCA2 gene?

Not At All				Very Much		
1	2	3	4	5	6	7

B46.

6

25. Do you feel you are adequately informed about what it would mean for your children if you had an altered BRCA1/BRCA2 gene?

Not At All				Very Much		
1	2	3	4	5	6	7

B47.

26. How confident are you that you will make the best decision in deciding whether to be tested for BRCA1/BRCA2?

Not At All				Very Much		
1	2	3	4	5	6	7

B48a.

27. How confident are you that you would cope effectively with a finding that you had an altered BRCA1/BRCA2 gene?

Not At All				Very Much		
1	2	3	4	5	6	7

B48b.

28. How confident are you that you would make the best decision concerning your options if you were found to have an altered BRCA1/BRCA2 gene?

Not At All				Very Much		
1	2	3	4	5	6	7

B48c.

29. How confident are you that you would be able to follow through and cope effectively over the long haul if you were found to have an altered BRCA1/BRCA2 gene?

Not At All				Very Much		
1	2	3	4	5	6	7

B48d.

RELATIONSHIPS SECTION

1. Is there anyone in your life with whom you can share your most private feelings
    without holding back?   **C21.**
            (1) ☐ Yes   (5) ☐ No

2. If married, can you share your most private feelings with your spouse/partner without
    holding back?   **C21a.**
            (1) ☐ Yes   (5) ☐ No

3. If married, is there anyone besides your spouse/partner with whom you can share
    your most private feelings without holding back?   **C21b.**

            (1) ☐ Yes   (5) ☐ No

LIFE EVENTS SECTION

1. Have any of the following events happened to you in <u>the past six months</u>?   **D1(a-m)**
    (Please Check All That Apply)

a. ☐ You retired, were fired, or laid off from work.	g. ☐ A close family member was seriously ill or injured.
b. ☐ You were unemployed and looking for work.	h. ☐ You had a marital separation or divorce.
c. ☐ Your spouse retired, was fired, or laid off from work.	i. ☐ You had serious troubles with relatives or close friends.
d ☐ Your spouse was unemployed and looking for work.	j. ☐ Your spouse had troubles or difficulties with relatives or close friends.
e. ☐ You had problems with the police or court.	k. ☐ A close family member died.
	l. ☐ A close friend or relative died.
f. ☐ You got into serious financial difficulties.	m. ☐ You were seriously ill or injured.

MARRIAGE SECTION

The following questions apply to persons who are <u>married or living with a partner</u>. *If you are not married or living with a partner, please check the box and skip to page 11, Mood Section.*

Not married or living with a partner ☐   **Ea.**

Most people have disagreements in their relationships. Please indicate by circling the number that represents the extent of agreement or disagreement experienced between you and your spouse/partner **DURING THE PAST MONTH**.

		Always Disagree	*Almost Always Disagree*	*Fre-quently Disagree*	*Occa-sionally Disagree*	*Almost Always Agree*	*Always Agree*	
1.	Religious matters	1	2	3	4	5	6	**H3.**
2.	Demonstration of affection	1	2	3	4	5	6	**H4.**
3.	Sex relations	1	2	3	4	5	6	**H6.**
4.	Conventionality (correct or proper behavior)	1	2	3	4	5	6	**H7.**
5.	Making major decisions	1	2	3	4	5	6	**H12.**
6.	Career decisions	1	2	3	4	5	6	**H15.**

		Never	*Rarely*	*Occa-sionally*	*More often than most*	*Most of the time*	*All of the time*	
7.	How often do you discuss or have you considered divorce, separation, or terminating your relationship?	1	2	3	4	5	6	**H16.**
8.	Do you ever regret that you married (or lived together)?	1	2	3	4	5	6	**H20.**
9.	How often do you and your partner quarrel?	1	2	3	4	5	6	**H21.**
10.	How often do you and your spouse/partner "get on each other's nerves?"	1	2	3	4	5	6	**H22.**

		None of Them	Very Few of Them	Some of Them	Most of Them	All of Them	
11.	To what extent do you and your spouse/partner share interests together?	1	2	3	4	5	H24.

How often would you say the following events occur between you and your spouse/partner?

		Never	Less than once a month	About twice a month	About twice a week	Once a day	More Often	
12.	Have a stimulating exchange of ideas	1	2	3	4	5	6	H25.
13.	Calmly discuss something	1	2	3	4	5	6	H27.
14.	Work together on a project	1	2	3	4	5	6	H28.

15. Considering **only the positive feelings** you have towards your spouse/partner, and **ignoring the negative ones**, please rate how positive these feelings are:　　　H33.

Not At All Positive								Extremely Positive	
1	2	3	4	5	6	7	8	9	10

16. Considering **only the negative feelings** you have towards your spouse/partner, and **ignoring the positive ones**, please rate how negative these feelings are:　　　H34.

Not At All Negative								Extremely Negative	
1	2	3	4	5	6	7	8	9	10

17. The following questions concern your spouse/partner's involvement in your health care.

		Never				Very Often	
a.	How often does your spouse/partner go with you to your appointments with doctors?	1	2	3	4	5	H35a.
b.	How often does your spouse/partner talk with your doctor or other medical personnel about your risk of breast or ovarian cancer?	1	2	3	4	5	H35b.
c.	How often does your spouse/partner keep track of what you need to do about your risk for breast or ovarian cancer?	1	2	3	4	5	H35c.
d.	How often does your spouse/partner change their activities to assist you in your health care?	1	2	3	4	5	H35d.

18. Has your spouse/partner attended individual, family or group sessions to become informed about your risk for breast or ovarian cancer and what can be done? **H36.**

               (1) ☐ Yes   (5) ☐ No

19. How much contact has your spouse/partner had with medical personnel concerning your risk for breast or ovarian cancer? **H37.**

    Very Little
     or None   A lot
      1   2   3   4   5   6   7

20. Do you feel your spouse/partner is adequately informed concerning your risk for breast or ovarian cancer and what can be done about it? **H38.**

    Not at All   Very Much
     1   2   3   4   5   6   7

21. To what extent are you satisfied with your spouse/partner's involvement in your health care? **H39.**

    Not at All   Very Much
     1   2   3   4   5   6   7

MOOD SECTION

1. In **the past year**, have you had two weeks or more when nearly every day you felt sad, blue, or depressed <u>or</u> in which you lost all interest in things like work or hobbies or things you usually liked to do for fun? **I12.**

          (1) ☐ Yes   (5) ☐ No (Skip to Question 2)

  1a.   During this period, did your work or relationships suffer? **I12a.**
        (1) ☐ Yes   (5) ☐ No

  1b.   During this period, did you get counseling or psychotherapy? **I12b.**
        (1) ☐ Yes   (5) ☐ No

  1c.   During this period, did you get medication for this condition? **I12c.**
        (1) ☐ Yes   (5) ☐ No

2. Are you **currently** receiving counseling, psychotherapy, or medication for depression or emotional problems? **I13.**

          (1) ☐ Yes   (5) ☐ No

SYMPTOMS OF STRAIN SECTION

LISTED BELOW ARE SOME SYMPTOMS OF STRAIN THAT PEOPLE SOMETIMES HAVE. *Please Read Each One Carefully And Check The Answer Which Best Reflects How Much That Symptom Has Bothered You During the **Past Three Months**.*

		Not at all	*A little*	*Quite a bit*	*Extremely*	
1.	Suddenly scared for no reason	1	2	3	4	K1.
2.	Feeling fearful	1	2	3	4	K2.
3.	Faintness, dizziness, or weakness	1	2	3	4	K3.
4.	Nervousness or shakiness inside	1	2	3	4	K4.
5.	Heart pounding or racing	1	2	3	4	K5.
6.	Trembling	1	2	3	4	K6.
7.	Feeling tense or keyed up	1	2	3	4	K7.
8.	Headaches	1	2	3	4	K8.
9.	Spells of terror or panic	1	2	3	4	K9.
10.	Feeling restless, can't sit still	1	2	3	4	K10.
11.	Feeling low in energy--slowed down	1	2	3	4	K11.
12.	Blaming yourself for things	1	2	3	4	K12.
13.	Crying easily	1	2	3	4	K13.
14.	Loss of sexual interest or pleasure	1	2	3	4	K14.
15.	Poor appetite	1	2	3	4	K15.
16.	Difficulty falling asleep, staying asleep	1	2	3	4	K16.
17.	Feeling hopeless about the future	1	2	3	4	K17.
18.	Feeling blue	1	2	3	4	K18.
19.	Feeling lonely	1	2	3	4	K19.
20.	Feeling trapped or caught	1	2	3	4	K20.
21.	Worrying too much about things	1	2	3	4	K21.
22.	Feeling no interest in things	1	2	3	4	K22.
23.	Thoughts of ending your life	1	2	3	4	K23.
24.	Feeling everything is an effort	1	2	3	4	K24.

25.	Feelings of worthlessness	1	2	3	4	K25.

COPING SECTION

1. Sometimes people can find unexpected benefits in difficulties. We are interested in the ways in which you might have made positive use of your risk for breast or ovarian cancer. For each of the statements below, indicate the degree to which your life is affected <u>positively</u> by your risk of breast or ovarian cancer.

		Not At All	A Very Small Degree	A Small Degree	A Moderate Degree	A Great Degree	A Very Great Degree	
a.	My priorities about what is important in life.	1	2	3	4	5	6	**L6a.**
b.	I'm more likely to try to change things which need changing.	1	2	3	4	5	6	**L6b.**
c.	An appreciation for the value of my own life.	1	2	3	4	5	6	**L6c.**
d.	A feeling of self-reliance.	1	2	3	4	5	6	**L6d.**
e.	A better understanding of spiritual matters.	1	2	3	4	5	6	**L6e.**
f.	Knowing that I can count on people in times of troubles.	1	2	3	4	5	6	**L6f.**
g.	A sense of closeness with others.	1	2	3	4	5	6	**L6g.**
h.	Knowing I can handle difficulties.	1	2	3	4	5	6	**L6h.**
i	A willingness to express my emotions.	1	2	3	4	5	6	**L6i.**
j.	Being able to accept the way things work out.	1	2	3	4	5	6	**L6j.**
k.	Appreciating each day.	1	2	3	4	5	6	**L6k.**
l.	Having compassion for others.	1	2	3	4	5	6	**L6l.**
m.	I'm able to do better things with my life.	1	2	3	4	5	6	**L6m.**
n.	New opportunities are available which wouldn't have been otherwise.	1	2	3	4	5	6	**L6n.**

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2. This set of questions deals with ways you've been coping with the stress in your life that comes with being at risk for breast or ovarian cancer. There are many ways people try to deal with problems. Obviously, different people deal with things in different ways, but we are interested in how you've tried to deal with it. Each item says something about a particular way of coping. We want to know *to what extent* you've been doing what the item says, how *much* or how *frequently*. Don't answer on the basis of whether it seems to be working but just whether or not you're doing it. Use these response choices below and try not to let one answer influence another. Please make your answers as true FOR YOU as you can.

		I haven't been doing this at all 1	I've been doing this a little bit 2	I've been doing this some 3	I've been doing this a lot 4	
a.	I've been turning to work or other activities to take my mind off things.	1	2	3	4	L7a.
b.	I've been concentrating my efforts on doing something about my situation.	1	2	3	4	L7b.
c.	I've been saying to myself "this isn't possible."	1	2	3	4	L7c.
d.	I've been using alcohol or other drugs to make myself feel better.	1	2	3	4	L7d.
e.	I've been getting emotional support from others.	1	2	3	4	L7e.
f.	I've been giving up trying to deal with it.	1	2	3	4	L7f.
g.	I've been taking action to try to make the situation better.	1	2	3	4	L7g.
h.	I've been refusing to believe that it is possible that I have an altered gene.	1	2	3	4	L7h.
i.	I've been saying things to let my unpleasant feelings escape.	1	2	3	4	L7i.
j.	I've been using alcohol or other drugs to help me get through it.	1	2	3	4	L7j.
k.	I've been trying to see it in a different light, to make it seem more positive.	1	2	3	4	L7k.
l.	I've been trying to come up with a strategy about what to do.	1	2	3	4	L7l.
m.	I've been getting comfort and understanding from someone.	1	2	3	4	L7m.

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		I haven't been doing this at all 1	I've been doing this a little bit 2	I've been doing this some 3	I've been doing this a lot 4	
n.	I've been giving up the attempt to cope.	1	2	3	4	L7n.
o.	I've been accepting the possibility that I might have an altered gene.	1	2	3	4	L7o.
p.	I've been expressing my negative feelings.	1	2	3	4	L7p.
q.	I've been trying to find comfort in my religion or spiritual beliefs.	1	2	3	4	L7q.
r.	I've been learning to live with the possibility that I might have the gene.	1	2	3	4	L7r.
s.	I've been thinking hard about what steps to take.	1	2	3	4	L7s.
t.	I've been praying or meditating.	1	2	3	4	L7t.
u.	I've been making fun of the situation.	1	2	3	4	L7u.

3. The following items are to be answered only by those women who are _married or living with a partner_.
   ☐ Not married or living with a partner   L8.
   (Skip to the last section on next page)

		I haven't been doing this at all 1	I've been doing this a little bit 2	I've been doing this some 3	I've been doing this a lot 4	
a.	I've been denying or hiding my anger around my spouse/partner.	1	2	3	4	L8a.
b.	I've been denying or hiding my worries around my spouse/partner.	1	2	3	4	L8b.
c.	I've been avoiding talking about my problems around my spouse/partner.	1	2	3	4	L8c.
d.	I've acted more positive around my spouse/partner than I feel.	1	2	3	4	L8d.

15

BACKGROUND DATA SECTION

These are a few questions about your religious background that we forgot to ask on the original questionnaire.

1. Religion:

Catholic	(1) ☐	Protestant	(4) ☐
Jewish	(2) ☐	Buddhist	(5) ☐
Muslim	(3) ☐	Other	(6) ☐
		None	(7) ☐

A3.

1a. How often do you attend religious services?

(1)
☐ Less Often Than Once a Month

(5)
☐ A Few Times A Month or More

A3a.

1b. How important are religious and spiritual beliefs in your life?

Not at All				Very Important
1	2	3	4	5

A3b.

Once again, We thank you for all of your valued participation in this study.

B.V. Post-Results Questionnaires

Post-Results 1 Questionnaire: 2 Month Follow-up
Post Results.2R Questionnaire Interview: 6 Month Follow-up
Post-Results Questionnaire: 6 Month Follow-up
Post-Results Questionnaire 3:   12 Month Follow-up

POST-RESULTS 1: *One to Two Months*

Genetic Testing Section

1. When did you receive your results of genetic testing? _____   B101

2. Are you the only person in your family who has gotten genetic testing for breast and ovarian cancer?
    (1) ☐ Yes   (5) ☐ No   B101a

3. What were the results of testing?   B101b

    1 ☐   Negative (uninformative) for BRCA1/BRCA2 and all Family members who were tested were negative for BRCA1/BRCA2 <u>OR</u> you are the only person in your family who has gotten testing (Skip to Question 4)

    2 ☐   Negative (informative) for BRCA1/BRCA2, but at least one family member was found to be Positive (Skip to Question 4)

    3 ☐   Positive for BRCA1/BRCA2 (Skip to Next page, Question 5)

4. When you took the test and found out that you <u>did not</u> have an altered gene associated with high risk for breast and ovarian cancer, what were your reactions?

		Strongly Disagree				*Strongly Agree*	N/A	
a.	I felt wonderful.	1	2	3	4	5	-8	B18a_a.
b.	I felt I had been told what I knew all along.	1	2	3	4	5	-8	B18a_b.
c.	I felt relieved.	1	2	3	4	5	-8	B18a_c.
d.	I did not believe the results.	1	2	3	4	5	-8	B18a_d.
e.	I fell apart emotionally.	1	2	3	4	5	-8	B18a_e.
f.	I felt guilty.	1	2	3	4	5	-8	B18a_f.
g.	I still felt anxious.	1	2	3	4	5	-8	B18a_g.
h.	I felt angry.	1	2	3	4	5	-8	B18a_h.
i.	I felt prepared for the future.	1	2	3	4	5	-8	B18a_i.
j.	I felt I had done all I needed to do.	1	2	3	4	5	-8	B18a_j.
k.	I did not feel very differently.	1	2	3	4	5	-8	B18a_k.

INTERVIEWER: Skip to Page 3, Question 6

5. When you took the test and found out that you **had** an altered gene associated with high risk for breast and ovarian cancer, what were your reactions?

		Strongly Disagree				Strongly Agree	N/A	
a.	I felt relieved about being more certain.	1	2	3	4	5.	-8	B19a_a.
b.	I felt I had been told what I knew all along.	1	2	3	4	5	-8	B19a_b.
c.	I did not believe the results.	1	2	3	4	5	-8	B19a_c.
d.	I felt guilty.	1	2	3	4	5	-8	B19a_d.
e.	I felt depressed.	1	2	3	4	5	-8	B19a_e.
f.	I felt worried about the future.	1	2	3	4	5	-8	B19a_f.
g	I fell apart emotionally.	1	2	3	4	5	-8	B19a_g.
h.	I felt anxious.	1	2	3	4	5	-8	B19a_h.
i.	I felt angry.	1	2	3	4	5	-8	B19a_i.
j.	I did not feel very differently.	1	2	3	4	5	-8	B19a_j.
k.	[For those who have daughters]. I wanted my daughters to be tested as soon as possible.	1	2	3	4	5	-8	B19a_k.

6. I am going to read a list of comments made by people after they have received their genetic test results. When you hear each comment, think about your thoughts and feelings toward the test results in terms of you. Please tell me how often each of the comments was true for you since you have received your test results, with the choices of *Not at All, Rarely, Sometimes,* and *Often.*

(INTERVIEWER NOTE: "IT" in the following questions refers to "RECEIVING TEST RESULTS")

		Not at All	Rarely	Sometimes	Often	
a.	I thought about it when I didn't mean to.	0	1	3	5	B116a.
b.	I avoided letting myself get upset when I thought about it or was reminded of it.	0	1	3	5	B116b.
c.	I tried to remove it from memory.	0	1	3	5	B116c.
d.	I had trouble falling asleep or staying asleep, because of pictures or thoughts about it that came into my mind.	0	1	3	5	B116d.
e.	I had waves of strong feelings about it.	0	1	3	5	B116e.
f.	I had dreams about it.	0	1	3	5	B116f.
g.	I stayed away from reminders of it.	0	1	3	5	B116g.
h.	I felt as if it hadn't happened or it wasn't real.	0	1	3	5	B116h.
i.	I tried not to talk about it.	0	1	3	5	B116i.
j.	Pictures about it popped into my mind.	0	1	3	5	B116j.
k.	Other things kept making me think about it.	0	1	3	5	B116k.
l.	I was aware that I still had a lot of feelings about it, but I didn't deal with them	0	1	3	5	B116l.
m.	I tried not to think about it.	0	1	3	5	B116m.
n.	Any reminder brought back feelings about it.	0	1	3	5	B116n.
o.	My feelings about it were kind of numb.	0	1	3	5	B116o.

Please answer the following two questions using a 1-5 scale, where 1=Not at All and 5=All the time

		Not At All			All The Time		
7	How often do you worry about developing breast cancer OR developing breast cancer again?	1	2	3	4	5	B27.
8.	To what extent do these worries interfere with your every day life?	1	2	3	4	5	B28.

Symptoms of Strain Section

LISTED BELOW ARE SOME SYMPTOMS OF STRAIN THAT PEOPLE SOMETIMES HAVE. Please listen to each one carefully and tell me the answer which best reflects how much that symptom has bothered you during the **PAST THREE MONTHS**. Please use the following scale: 1=Not at all, 2=A little, 3=Quite a bit, and 4=Extremely.

		Not at all	A little	Quite a bit	Extremely	
1.	Suddenly scared for no reason	1	2	3	4	K1.
2.	Feeling fearful	1	2	3	4	K2.
3.	Faintness, dizziness, or weakness	1	2	3	4	K3.
4.	Nervousness or shakiness inside	1	2	3	4	K4.
5.	Heart pounding or racing	1	2	3	4	K5.
6.	Trembling	1	2	3	4	K6.
7.	Feeling tense or keyed up	1	2	3	4	K7.
8.	Headaches	1	2	3	4	K8.
9.	Spells of terror or panic	1	2	3	4	K9.
10.	Feeling restless, can't sit still	1	2	3	4	K10.
11.	Feeling low in energy--slowed down	1	2	3	4	K11.
12.	Blaming yourself for things	1	2	3	4	K12.
13.	Crying easily	1	2	3	4	K13.
14.	Loss of sexual interest or pleasure	1	2	3	4	K14.
15.	Poor appetite	1	2	3	4	K15.
16.	Difficulty falling asleep, staying asleep	1	2	3	4	K16.
17.	Feeling hopeless about the future	1	2	3	4	K17.
19.	Feeling blue	1	2	3	4	K19.
19.	Feeling lonely	1	2	3	4	K19.
20.	Feeling trapped or caught	1	2	3	4	K20.
21.	Worrying too much about things	1	2	3	4	K21.
22.	Feeling no interest in things	1	2	3	4	K22.
23.	Thoughts of ending your life	1	2	3	4	K23.
24.	Feeling everything is an effort	1	2	3	4	K24.
25.	Feelings of worthlessness	1	2	3	4	K25.

26. Are the sypmtoms we just talked about related to your receiving your genetic test results?

Yes	No
1	5

K26

Open-ended Questions:

1.   Do you feel you were given adequate information before receiving your genetic results?   B117.

_____

_____

_____

_____

_____

1a.   Was there anything omitted that would have been helpful?   B117a.

_____

_____

_____

_____

1b.   What information was most helpful?   B117b.

_____

_____

_____

_____

_____

2.	What was the most effective or helpful thing you did to cope during this process?	B118.

_____

_____

_____

_____

_____

_____

_____

3.	Were there any things you did that were not helpful? What were they?	B119.

_____

_____

_____

_____

_____

_____

4.	Who has been the most helpful during this time? (Make a listing in order R gives you)	B120.

1. _____	5. _____

2. _____	6. _____

3. _____	7. _____

4. _____	8. _____

4a.	If the list has more than one person, Who has been most helpful?	B120a.

_____

_____

4b. What did they do for you?   B120b.

_____

_____

_____

_____

_____

_____

_____

5.   Has there been anything someone did that was not helpful?   B121.

_____

_____

_____

_____

_____

_____

_____

_____

6. Are you currently Married or Living in a steady marriage-like relationship?   B122.

     (1) ☐ Yes
     (5) ☐ No (Skip to next page, question 9)

If YES and R has not yet discussed her spouse/partner's support:

7. What's the most helpful thing your spouse/partner has done or is doing for you?   B123.

_____

_____

_____

_____

_____

_____

8. What's the most helpful thing your spouse could do for you?   B124.

_____

_____

_____

_____

_____

_____

_____

9. Is there anything you plan to do immediately with this information?   B125.

_____

_____

_____

_____

_____

_____

10. What would you tell someone who is contemplating genetic testing?   B126.

_____

_____

_____

_____

_____

_____

11. Do you have any regrets about getting this testing? If yes, what are they?   B127.

_____

_____

_____

_____

_____

_____

12. Are you the first person in your family to get testing?   B128.

_____

_____

_____

_____

_____

13. Will you encourage your relatives to get genetic testing or discourage them from testing?   B129.

_____

_____

_____

_____

_____

_____

14. We are trying to get a better picture of this process. What is something I didn't ask you that I   B130.
should have?

_____

_____

_____

_____

_____

_____

_____

_____

POST-RESULTS INTERVIEW--*Six Month Follow-Up*

INTERVIEWER: For the Introduction, Please include the following important points or read the script:

- Thank the subject again for her participation (We know we've asked a lot of her.)
- This interview is 6 months after receiving genetic test results.
- Repetition of Questions needed to compare results to our previous research and to other researchers.
- Remind subject that this interview is confidential and completely voluntary.
- Suggest that the subject may prefer to get a pen and paper to jot down the different scales that will be used.

We have asked you a lot of questions over the last several years while you were waiting for your genetic results. This interview is scheduled 6 months after you received genetic test results. We recognize that we asked many of these questions before. They are the "gold" standards in this kind of research and in order to compare our results with other researchers we need to ask them again. As you know, offering of genetic testing for breast and ovarian cancer is still relatively new and genetic counselors rely on research like this to plan services. We know that we've asked a lot of you. Thanks again for all your patience.

---

(1) ☐ Affected   (0) ☐ Unaffected

For AFFECTED Subjects Only:

1. First of all...Before your own diagnosis of cancer (breast or ovarian), Did you believe that you were a member of a family at high risk for breast and ovarian cancer?

    (1) ☐ Yes   (5) ☐ No   N1

Researchers are always interested in stress.

Standardized measures of stressful life events have been established with 0 representing no stress and 100 representing the greatest stress. To give you some reference points, here are some examples:

Change in residence is assigned a stress score of <u>20</u>
Pregnancy is <u>40</u>
Death of a close family member is <u>63</u>
Death of a spouse is <u>100</u>

Keeping in mind the ratings I just mentioned:

2. How would you rate the stress of being a member of a family at increased risk of breast and ovarian cancer?　　N2

　　Being a member of a high risk family _____

3.

UNAFFECTED:	AFFECTED:
Hypothetically....	Thinking about when you were first diagnosed with cancer (breast or ovarian)...

How would you rate the stress of being diagnosed with cancer?

　　Diagnosis of cancer _____　　N3

4. Now, how would you rate the stress of receiving your test results? [By that , I only am referring to the time at which you actually received your results.]

　　Stress of receiving results_____　　N4

5. When you signed up for the study and gave your blood sample, rate how stressful you <u>thought</u> receiving your test results would be?

　　Stress you had thought getting your test results WOULD be _____　　N5

6. Some women tell us that the whole process of getting results went very smoothly, while others tell us that it was an ordeal. Women have been both pleased and annoyed by the information they received or did not receive, the way results were given - that sort of thing. Using our stress ratings, how would you rate the process you went through to get results?

　　Process to get results _____　　N6

6a. What about the process has been stressful? Do you have any suggestions for how the process could be improved?　　N6a

_____

_____

_____

(more space over) _____

_____

_____

_____

_____

Next, we are interested in any recent events in your family related to cancer and risk for cancer. In the past 6 months...

7.   To your knowledge, have any of your family members received genetic test results in the past 6 months? What is their relationship to you? Do you know if a mutation was found? Positive or Negative?

(1) ☐ Yes   (5) ☐ No (Skip to Next Question)

Total # Received Results: _____   N8t

Relationship to R:	Positive Mutation Found	Negative No Mutation Found	Don't Know	
a.		1	0	-9	N8a
b.		1	0	-9	N8b
c.		1	0	-9	N8c

8.   Have any family members declined receiving test results (in the past 6 months)?

(1) ☐ Yes   (5) ☐ No (Skip to Next Question)

Total # Declined Results: _____   N9t

Relationship to R:	
a.		N9a
b.		N9b
c.		N9c

9.   Have any family members received a new diagnosis of cancer (in the past 6 months)?

(1) ☐ Yes   (5) ☐ No (Skip to Next Question)

Total # New Diagnosis: _____   N10t

Relationship to R:	
a.		N10a
b.		N10b
c.		N10c

10. Have any family members had prophylactic surgery (in the past 6 months)?

(1) ☐ Yes   (5) ☐ No (Skip to Next Question)

N11

Total # Prophylactic Surgery: _____

	Relationship to R:	Prophylactic Procedure:	
a.			N11a
b.			N11b
c.			N11c

11. Have any family members had any other things happen related to cancer or risk of cancer (in the past 6 months)? [such as treatment, surgery, or death?]

(1) ☐ Yes   (5) ☐ No (Skip to Next Question)

N12

Total # Family Members with a Cancer Related Event: _____

	Relationship to R:	Event related to cancer:	
a.			N12a
b.			N12b
c.			N12c

12. Using a 5 point scale where 1=Not at All, 2-Rarely, 3=Sometimes, 4=Often, and 5=A Lot, Could you please tell us how often you talk with the following people in your family? If you have more than one close relative in a category, please answer the question thinking about the relative with whom you talk most frequently. How often do you talk with your _____ ?

		Not at All	Rarely	Sometimes	Often	A Lot	Not Applicable	
a.	Spouse	1	2	3	4	5	-8	N28a
b.	Daughter	1	2	3	4	5	-8	N28b
c.	Son	1	2	3	4	5	-8	N28c
d.	Mother	1	2	3	4	5	-8	N28d
e.	Grandmother	1	2	3	4	5	-8	N28e
f.	Sister	1	2	3	4	5	-8	N28f
g.	Aunt	1	2	3	4	5	-8	N28g
h.	Cousin	1	2	3	4	5	-8	N28h

13. Using the same scale, How often do you talk with each of these same people when something important and/or difficult happens in your life?

		Not at All	Rarely	Sometimes	Often	A Lot	Not Applicable	
a.	Spouse	1	2	3	4	5	-8	N29a
b.	Daughter	1	2	3	4	5	-8	N29b
c.	Son	1	2	3	4	5	-8	N29c
d.	Mother	1	2	3	4	5	-8	N29d
e.	Grandmother	1	2	3	4	5	-8	N29e
f.	Sister	1	2	3	4	5	-8	N29f
g.	Aunt	1	2	3	4	5	-8	N29g
h.	Cousin	1	2	3	4	5	-8	N29h

14. Before you actually got your results, How often did you discuss getting genetic testing for breast and ovarian cancer with these family members?

		Not at All	Rarely	Sometimes	Often	A Lot	Not Applicable	
a.	Spouse	1	2	3	4	5	-8	N30a
b.	Daughter	1	2	3	4	5	-8	N30b
c.	Son	1	2	3	4	5	-8	N30c
d.	Mother	1	2	3	4	5	-8	N30d
e.	Grandmother	1	2	3	4	5	-8	N30e
f.	Sister	1	2	3	4	5	-8	N30f
g.	Aunt	1	2	3	4	5	-8	N30g
h.	Cousin	1	2	3	4	5	-8	N30h

15. In the last six months since you received your genetic test results, How often have you discussed the results with each of them?

		Not at All	Rarely	Sometimes	Often	A Lot	Not Applicable	
a.	Spouse	1	2	3	4	5	-8	N31a
b.	Daughter	1	2	3	4	5	-8	N31b
c.	Son	1	2	3	4	5	-8	N31c
d.	Mother	1	2	3	4	5	-8	N31d

		Not at All	Rarely	Sometimes	Often	A Lot	Not Applicable	
e.	Grandmother	1	2	3	4	5	-8	N31e
f.	Sister	1	2	3	4	5	-8	N31f
g.	Aunt	1	2	3	4	5	-8	N31g
h.	Cousin	1	2	3	4	5	-8	N31h

16. Overall, to what extent do your family members talk about themselves as being a family at high risk for breast or ovarian cancer?   N32

Not at All	Rarely	Sometimes	Often	A Lot
1	2	3	4	5

Related Comments: _____

_____

_____

_____

_____

_____

17. When you catch-up on what's going on in your family, to what extent are people's experiences with breast or ovarian cancer a topic of conversation?   N33

Not at All	Rarely	Sometimes	Often	A Lot
1	2	3	4	5

Related Comments: _____

_____

_____

_____

_____

_____

18. In your family, to what extent do you agree on how to manage risk for breast or ovarian cancer? N34

Not at All	Rarely	Sometimes	Often	A Lot
1	2	3	4	5

Can you give me some examples of ways this comes up? _____

_____

_____

_____

Have there been any disagreements about managing risk for cancer in your family? Can you tell me about that? _____

_____

_____

_____

_____

For those receiving uninformative results (No BRCA1 and BRCA2 Alterations Found AND No one in their family has a BRCA1 or BRCA2 alteration even though there is a family history of breast cancer):

19. Even though no alteration was found for BRCA1 and BRCA2, Do you believe there is a possibility that you have another altered gene conveying an increased risk for breast and ovarian cancer?

    (1) ☐ Yes   (5) ☐ No   N13

20. If it becomes available, do you intend to get testing for any additional genes related to risk of breast and ovarian cancer?

    (1) ☐ Yes   (5) ☐ No   (3) ☐ Unsure   N14

Now I want to ask you about the impact receiving results had on you. I'm going to ask you to rate the effect that getting your genetic results has had on different areas in your life. Using a scale of 1-5, 1=Very Negative Effect, 2=Somewhat Negative Effect, 3=No Effect, 4=Somewhat Positive Effect, and 5=Very Positive Effect...

21. On the whole, what effect has testing had on <u>your life</u>?

Very Negative Effect	Somewhat Negative Effect	No Effect	Somewhat Positive Effect	Very Positive Effect	
1	2	3	4	5	N15

22. Think about your everyday _family life_. What effect would you say getting the genetic test results has had?

Very Negative Effect	Somewhat Negative Effect	No Effect	Somewhat Positive Effect	Very Positive Effect	
1	2	3	4	5	N16

23. What effect has getting your results had on your _work_ in and outside of the home?

Very Negative Effect	Somewhat Negative Effect	No Effect	Somewhat Positive Effect	Very Positive Effect	
1	2	3	4	5	N17

24. What effect has getting your results had on your concerns for your _child's/children's future_?

Very Negative Effect	Somewhat Negative Effect	No Effect	Somewhat Positive Effect	Very Positive Effect	
1	2	3	4	5	N19

25. Has getting these results changed the likelihood that you will have (more) children?

No/Fewer Children	No Change	More Children	
1	2	3	N22

26. How has it affected your anxiety about the _future_?

Less Anxiety	No Change	More Anxiety	
1	2	3	N18

N20

27. Are there any OTHER areas that testing has affected?

(1) ☐ Yes   (5) ☐ No

N20a

27a. Please List Other Areas Affected by Genetic testing:

_____

_____

(more space over) _____

Now using a different scale of 1-5, 1=Not at All, 2=A Little, 3=Some, 4=Quite a Bit, and 5=Very Much...

28.   How much has getting test results changed your health care decision(s)?

Not At All	A Little	Some	Quite a Bit	Very Much
1	2	3	4	5

N21

29.   In general, how much has getting genetic results changed your life?

Not At All	A Little	Some	Quite a Bit	Very Much
1	2	3	4	5

N23

Symptoms of Strain Section

I'm going to be reading you some Symptoms Of Strain that people sometimes have. Please listen to each one carefully and tell me the answer which best reflects how much that symptom has BOTHERED you during the **PAST THREE MONTHS**. Please use the following scale: 1=Not at all, 2=A little, 3=Quite a bit, and 4=Extremely.

		Not at all	_A little_	_Quite a bit_	_Extremely_	
1.	Suddenly scared for no reason	1	2	3	4	K1.
2.	Feeling fearful	1	2	3	4	K2.
3.	Faintness, dizziness, or weakness	1	2	3	4	K3.
4.	Nervousness or shakiness inside	1	2	3	4	K4.
5.	Heart pounding or racing	1	2	3	4	K5.
6.	Trembling	1	2	3	4	K6.
7.	Feeling tense or keyed up	1	2	3	4	K7.
8.	Headaches	1	2	3	4	K8.
9.	Spells of terror or panic	1	2	3	4	K9.
10.	Feeling restless, can't sit still	1	2	3	4	K10.

		Not at all	A little	Quite a bit	Extremely	
11.	Feeling low in energy--slowed down	1	2	3	4	K11.
12.	Blaming yourself for things	1	2	3	4	K12.
13.	Crying easily	1	2	3	4	K13.
14.	Loss of sexual interest or pleasure	1	2	3	4	K14.
15.	Poor appetite	1	2	3	4	K15.
16.	Difficulty falling asleep, staying asleep	1	2	3	4	K16.
17.	Feeling hopeless about the future	1	2	3	4	K17.
18.	Feeling blue	1	2	3	4	K18.
19.	Feeling lonely	1	2	3	4	K19.
20.	Feeling trapped or caught	1	2	3	4	K20.
21.	Worrying too much about things	1	2	3	4	K21.
22.	Feeling no interest in things	1	2	3	4	K22.
23.	Thoughts of ending your life	1	2	3	4	K23.
24.	Feeling everything is an effort	1	2	3	4	K24.
25.	Feelings of worthlessness	1	2	3	4	K25.

K26. To what extent are these current symptoms a result of getting genetic testing?

Not At All	A Little	Some	Quite a Bit	Very Much	
1	2	3	4	5	K26

The following questions are about any counseling or psychotherapy you have received in the past, either related to cancer issues or other personal issues.

30.　Have you <u>ever</u> seen any kind of counselor, therapist, psychologist, psychiatrist, or any other person like that for personal or emotional problems? (ASK the following probes as necessary: What type of person did you see? Why did you go? Have you ever seen someone for cancer issues? For dealing with Genetic Testing?)

Outpatient psychiatric or psychological treatment or counseling in the past 12 months:
- Exclude Educational Sessions with a Genetic Counselor
- Include treatment in outpatient and day hospital settings
- guidance or vocational counseling = No
- Axis I-type symptoms, even if not diagnosed = 3
- bereavement counseling = 4
- didactic analysis or equivalent ONLY for training/education = 8
- Family therapy ONLY to help a family member (subject did not discuss his/her own problems) = 8

Code all reasons that apply Next Page

CODE ALL REASONS THAT APPLY:

a ☐ NO (Skip to Question N25)   N24a

b ☐ YES - Depression   N24b

c ☐ YES - Other Psychiatric (Axis I)   N24c

d ☐ YES - Interpersonal, Behavioral, Stress, Family, Developmental, etc.   N24d

e ☐ YES - Cancer Issues (diagnosis)   N24e

f ☐ YES - Genetic Testing Issues   N24f

g ☐ YES - Other (Specify Next page) _____   N24g

Specify treatment(s) and problem(s) _____

_____

_____

_____

_____

31. Are you <u>currently</u> seeing any kind of counselor, therapist, psychologist, psychiatrist, or any other person like that for personal or emotional problems? (ASK the following probes as necessary: What type of person are you seeing? Why are you going? Are you seeing someone for cancer issues? For dealing with Genetic Testing?)

Outpatient psychiatric or psychological treatment or counseling in the past 12 months:
- Exclude Educational Sessions with a Genetic Counselor
- Include treatment in outpatient and day hospital settings
- guidance or vocational counseling = No
- Axis I-type symptoms, even if not diagnosed = 3
- bereavement counseling = 4
- didactic analysis or equivalent ONLY for training/education = 8
- Family therapy ONLY to help a family member (subject did not discuss his/her own problems) = 8

CODE ALL REASONS THAT APPLY:

a ☐ NO (Skip to Question N26)   N25a

b ☐ YES - Depression   N25b

c ☐ YES - Other Psychiatric (Axis I)   N25c

d ☐ YES - Interpersonal, Behavioral, Stress, Family, Developmental, etc.   N25d

e ☐ YES - Cancer Issues (diagnosis)   N25e

f ☐ YES - Genetic Testing Issues   N25f

g ☐ YES - Other (Specify) _____   N25g

Specify treatment(s) and problem(s) _____

_____

_____

_____

_____

32. Have you ever taken medication for emotional distress, depression, or anxiety?

       (1) ☐ Yes (Record Meds below)   (5) ☐ No (Skip to Score Hopkins)

33. What medication(s) did you take? How long did you take this medication? Are you still taking this medication? Were the reasons for <u>starting</u> this medication related to your cancer or your risk for cancer? Were the reasons for <u>starting</u> this medication related to your genetic testing or receiving genetic test results?

      Medications for emotional distress, depression, or anxiety:
- Inlude St. John's Wart
- Exclude Hormonal Treatment and other herbs

	Medication:	Code:	Duration (Months)	Currently Taking?	Related to Cancer ?	Related to Genetic Testing?	
a.				(1) ☐Yes (5) ☐No	(1) ☐Yes (5) ☐No	(1) ☐Yes (5) ☐No	N27a
b.				(1) ☐Yes (5) ☐No	(1) ☐Yes (5) ☐No	(1) ☐Yes (5) ☐No	N27b
c.				(1) ☐Yes (5) ☐No	(1) ☐Yes (5) ☐No	(1) ☐Yes (5) ☐No	N27c
d.				(1) ☐Yes (5) ☐No	(1) ☐Yes (5) ☐No	(1) ☐Yes (5) ☐No	N27d
e.				(1) ☐Yes (5) ☐No	(1) ☐Yes (5) ☐No	(1) ☐Yes (5) ☐No	N27e
f.				(1) ☐Yes (5) ☐No	(1) ☐Yes (5) ☐No	(1) ☐Yes (5) ☐No	N27f

INTERVIEWER: Go back to Score Hopkins-25 (Symptoms of Strain Section, p. 8) by adding up the numbered answers for K1-K25:

Score _____

If score = "44 or more," <u>Complete</u> SCID modules

If score = "43 or less," <u>Skip</u> SCID modules

SCID Completed
☐

WHEN FINISHED WITH INTERVIEW BE SURE TO TELL SUBJECT:

- We have a short questionnaire that we well mail in about a week with some different questions.

- We'd like to contact everyone (one last time) in about 6 months, if that is okay.

- Check Address

- Thank subject.

WOMEN'S HEALTH STUDY
Post-Results Questionnaire
6 Month Follow-Up

POST-RESULTS.2 QUESTIONNAIRE--*Six Month Follow-Up*

Genetic Testing Section

First, we would like to ask some questions about your reactions to receiving your genetic test results and their impact on your life.

1. How distressed were you when you received your genetic test results?

Not At All Distressed				Very Distressed
1	2	3	4	5

B69b

2. Overall, do you regret the decision to obtain your results?

Not At All				Very Much So
1	2	3	4	5

B71a

3. We are interested in the decisions women make after being notified of the results of their testing. *After* obtaining your results, are you now considering any of these options? Please circle only one response for each option.

		Done Before Obtaining Results	Definitely Will NOT Do	Probably Will NOT Do	Probably Will Do	Definitely Will Do	Done After Obtaining Results	Does Not Apply to Me	
a.	Prophylactic Oophorectomy	0	1	2	3	4	5	-8	B103a
b.	Prophylactic Mastectomy	0	1	2	3	4	5	-8	B103b
c.	Monthly Breast Self-Exams	0	1	2	3	4	5	-8	B103c
d.	Yearly Physical Exams	0	1	2	3	4	5	-8	B103d
e.	Mammograms at least once a year	0	1	2	3	4	5	-8	B103e
f.	Encouraging my relatives to be tested	0	1	2	3	4	5	-8	B103f
g.	Discouraging my relatives from being tested	0	1	2	3	4	5	-8	B103g
h.	Telling some of my relatives what my results were	0	1	2	3	4	5	-8	B103h

4. For each of the following areas of your life, please indicate how much these decisions/plans have been affected by the results of genetic testing?

		Not at all Affected				Very Much Affected	Not Applicable	
a.	Decisions about having children	1	2	3	4	5	-8	B35c
b.	Decisions about forms of birth control	1	2	3	4	5	-8	B36c
c.	Decisions about which steps to take to prevent breast cancer	1	2	3	4	5	-8	B37c
d.	Decisions about work and career	1	2	3	4	5	-8	B38c
e.	Decisions about savings and financial planning	1	2	3	4	5	-8	B39c
f.	Plans for your future	1	2	3	4	5	-8	B40c
g.	Plans for your daughter's future	1	2	3	4	5	-8	B42c

5. [Now that you have received genetic results and have more information about your risk of developing breast or ovarian cancer,] After receiving your genetic test results, how likely do you think you are to develop breast or ovarian cancer (or develop breast or ovarian cancer again), compared to **the average woman**? (Please circle one)   B7a

Much Less Likely				Much More Likely
1	2	3	4	5

6. After receiving your genetic test results, how likely do you think you are to develop breast or ovarian cancer (or develop breast or ovarian cancer again), compared to **the women in your family**?   B8a (Please circle one)

Much Less Likely				Much More Likely
1	2	3	4	5

7. Overall, what do you believe your risk to be of developing breast or ovarian cancer (or developing breast or ovarian cancer again) **in the near future**?   B6

0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
0	1	2	3	4	5	6	7	8	9	10

8. Overall, what do you believe your risk to be of developing breast or ovarian cancer (or developing breast or ovarian cancer again) **at some point in your lifetime?**   B7

0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
0	1	2	3	4	5	6	7	8	9	10

9. Now, we would like to ask you some questions about worries you may or may not experience.

		Not At All				All The Time	
a.	How often do you worry about developing breast cancer or developing breast cancer again?	1	2	3	4	5	B27
b.	To what extent do these worries interfere with your every day life?	1	2	3	4	5	B28
c.	How often do you worry about developing ovarian cancer or developing ovarian cancer again?	1	2	3	4	5	B110
d.	To what extent do these worries interfere with your every day life?	1	2	3	4	5	B111
e.	How often do you worry about **your relatives** developing breast or ovarian cancer?	1	2	3	4	5	B106
f.	To what extent do these worries interfere with your every day life?	1	2	3	4	5	B107
g.	How often do you worry about **your relatives** having an altered gene associated with risk for breast and ovarian cancer?	1	2	3	4	5	B108
h.	To what extent do these worries interfere with your every day life?	1	2	3	4	5	B109

Coping Section

1. How confident are you that **you** are coping effectively after getting your genetic test results?

Not At All Confident						Very Confident	
1	2	3	4	5	6	7	B48e

2. How confident are you that **your family members** are coping effectively with the results of your genetic testing?

Not At All Confident						Very Confident
1	2	3	4	5	6	7

B48f

3. Sometimes people can find unexpected benefits in difficulties. We are interested in the ways in which you might have made positive use of genetic test results. For each of the statements below, indicate the degree to which your life has been affected <u>positively</u> by finding out your results.

		Not At All	A Very Small Degree	A Small Degree	A Moderate Degree	A Great Degree	A Very Great Degree	
a.	My priorities about what is important in life.	1	2	3	4	5	6	L6a
b.	I'm more likely to try to change things which need changing.	1	2	3	4	5	6	L6b
c.	An appreciation for the value of my own life.	1	2	3	4	5	6	L6c
d.	A feeling of self-reliance.	1	2	3	4	5	6	L6d
e.	A better understanding of spiritual matters.	1	2	3	4	5	6	L6e
f.	Knowing that I can count on people in times of troubles.	1	2	3	4	5	6	L6f
g.	A sense of closeness with others.	1	2	3	4	5	6	L6g
h.	Knowing I can handle difficulties.	1	2	3	4	5	6	L6h
i.	A willingness to express my emotions.	1	2	3	4	5	6	L6i
j.	Being able to accept the way things work out.	1	2	3	4	5	6	L6j
k.	Appreciating each day.	1	2	3	4	5	6	L6k
l.	Having compassion for others.	1	2	3	4	5	6	L6l
m.	I'm able to do better things with my life.	1	2	3	4	5	6	L6m

		Not At All	A Very Small Degree	A Small Degree	A Moderate Degree	A Great Degree	A Very Great Degree	
n.	New opportunities are available which wouldn't have been otherwise.	1	2	3	4	5	6	L6n
o.	Putting effort into my relationships.	1	2	3	4	5	6	L6o
p.	I have a stronger religious faith.	1	2	3	4	5	6	L6p
q.	I discovered that I'm stronger than I thought I was.	1	2	3	4	5	6	L6q
r.	I learned a great deal about how wonderful people are.	1	2	3	4	5	6	L6r
s.	I developed new interests.	1	2	3	4	5	6	L6s
t.	I accept needing others.	1	2	3	4	5	6	L6t
u.	I established a new path for my life.	1	2	3	4	5	6	L6u

5. Below is a list of comments made by people after they have received their genetic test results. When you read each comment, think about your thoughts and feelings toward the test results. Please indicate how often each of the comments was true for you since you received your test results, with the choices of *Not at All, Rarely, Sometimes,* and *Often.*

"IT" in the following questions refers to "RECEIVING YOUR TEST RESULTS")		Not at All	Rarely	Sometimes	Often	
a.	I thought about it when I didn't mean to.	0	1	3	5	B116a
b.	I avoided letting myself get upset when I thought about it or was reminded of it.	0	1	3	5	B116b
c.	I tried to remove it from memory.	0	1	3	5	B116c
d.	I had trouble falling asleep or staying asleep, because of pictures or thoughts about it that came into my mind.	0	1	3	5	B116d
e.	I had waves of strong feelings about it.	0	1	3	5	B116e
f.	I had dreams about it.	0	1	3	5	B116f
g.	I stayed away from reminders of it.	0	1	3	5	B116g

"IT" in the following questions refers to "RECEIVING YOUR TEST RESULTS")	Not at All	Rarely	Sometimes	Often	
h.	I felt as if it hadn't happened or it wasn't real.	0	1	3	5	B116h
i.	I tried not to talk about it.	0	1	3	5	B116i
j.	Pictures about it popped into my mind.	0	1	3	5	B116j
k.	Other things kept making me think about it.	0	1	3	5	B116k
l.	I was aware that I still had a lot of feelings about it, but I didn't deal with them	0	1	3	5	B116l
m.	I tried not to think about it.	0	1	3	5	B116m
n.	Any reminder brought back feelings about it.	0	1	3	5	B116n
o.	My feelings about it were kind of numb.	0	1	3	5	B116o

Mood Section

1. In the past 6 months, have you had two weeks or more when nearly every day you felt sad, blue, or depressed or in which you lost all interest in things like work or hobbies or things you usually liked to do for fun?   I12

    (1) ☐ Yes   (5) ☐ No (Skip to Health Section, Next Page)

    1a.   During this period, did your work or relationships suffer?   I12a
          (1) ☐ Yes   (5) ☐ No

    1b.   During this period, did you get counseling or psychotherapy?   I12b
          (1) ☐ Yes   (5) ☐ No

    1c.   During this period, did you get medication for this condition?   I12c
          (1) ☐ Yes   (5) ☐ No

Health Section

1. How often do you usually get a mammogram?
   - 1 ☐ Never (I have never had a mammogram).
   - 2 ☐ Less than Once a Year
   - 3 ☐ Once a Year
   - 4 ☐ More than Once a Year
   - -8 ☐ Does Not Apply because of surgery

2. How often do you perform self-examination of your breasts?
   - 1 ☐ Never or rarely
   - 2 ☐ Less than Once a Month
   - 3 ☐ Monthly
   - 4 ☐ More than Once a Month
   - -8 ☐ Does Not Apply because of surgery

3. How often do you get CA-125 screening for ovarian cancer?
   - 1 ☐ Never (I have never had a CA-125 screening).
   - 2 ☐ Less than Once a Year
   - 3 ☐ Once a Year
   - 4 ☐ More than Once a Year
   - -8 ☐ Does Not Apply because of surgery

4. How often do you get ultrasound screening for ovarian cancer?
   - 1 ☐ Never (I have never had an ovarian ultrasound for cancer screening).
   - 2 ☐ Less than Once a Year
   - 3 ☐ Once a Year
   - 4 ☐ More than Once a Year
   - -8 ☐ Does Not Apply because of surgery

5. Has knowing your genetic results affected your **motivation** to perform breast self examination as **frequently** as needed?

Decreased Motivation		No Effect		Increased Motivation	Does Not Apply because of surgery
1	2	3	4	5	-8

6. Has knowing your genetic results affected your **confidence** that you will perform breast self examination as **frequently** as needed?

Decreased Confidence		No Effect		Increased Confidence	Does Not Apply because of surgery
1	2	3	4	5	-8

7. Has knowing your genetic results affected your **confidence** that you will perform breast self examination as **carefully and competently** as needed?

Decreased Confidence	No Effect			Increased Confidence	Does Not Apply because of surgery
1	2	3	4	5	-8

B34f

8. How confident are you that you would be able to detect a change in your breasts using breast self examination?

Not At All						Very Much So	Does Not Apply because of surgery
1	2	3	4	5	6	7	-8

B34c

I1

9. In general, would you say your health is:

1 ☐ Excellent   2 ☐ Very Good   3 ☐ Good   4 ☐ Fair   5 ☐ Poor

10. Compared to one year ago, how would you rate your health in general now? (Please Check One)   I2

1 ☐ Much better now than one year ago
2 ☐ Somewhat better now than one year ago
3 ☐ About the same as one year ago
4 ☐ Somewhat worse now than one year ago
5 ☐ Much worse than one year ago

11. **During the past 4 weeks**, have you had any of the following problems with your work or other regular daily activities as a result of any **emotional** problems (such as feeling depressed or anxious)?

		Yes	No	
a.	Cut down the amount of time you spent on work or other activities.	1	5	I5a
b.	Accomplished less than you would like.	1	5	I5b
c.	Didn't do work or other activities as carefully as usual.	1	5	I5c

12. **During the past 4 weeks**, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?   I6

1 ☐ Not at all   2 ☐ Slightly   3 ☐ Moderately   4 ☐ Quite a bit   5 ☐ Extremely

13. How much bodily pain have you had **during the past 4 weeks**?   I7

1 ☐ None   2 ☐ Very Mild   3 ☐ Mild   4 ☐ Moderate   5 ☐ Severe   6 ☐ Very Severe

14. **During the past 4 weeks**, how much did pain interfere with your normal work (including both work outside the home and housework)?   I8

1 ☐ Not at all   2 ☐ Slightly   3 ☐ Moderately   4 ☐ Quite a bit   5 ☐ Extremely

15. These questions are about how you feel and how things have been with you during the past **4 weeks**. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time **during the past 4 weeks:** *Please mark the appropriate box to indicate your response.*

		All of the time	*Most of the time*	*A good bit of the time*	*Some of the time*	*A little of the time*	*None of the time*	
a.	Did you feel full of pep?	1	2	3	4	5	6	I9a
b.	Have you been a very nervous person?	1	2	3	4	5	6	I9b
c.	Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6	I9c
d.	Have you felt calm and peaceful?	1	2	3	4	5	6	I9d
e.	Did you have a lot of energy?	1	2	3	4	5	6	I9e
f.	Have you felt downhearted and blue?	1	2	3	4	5	6	I9f
g.	Did you feel worn out?	1	2	3	4	5	6	I9i
h.	Have you been a happy person?	1	2	3	4	5	6	I9g
i.	Did you feel tired?	1	2	3	4	5	6	I9h

16. **During the past 4 weeks**, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?   I10

    1 ☐ All of the time
    2 ☐ Most of the time
    3 ☐ Some of the time
    4 ☐ A little of the time
    5 ☐ None of the time

17. How **TRUE** or **FALSE** is each of the following statements for you?

		Definitely True	*Mostly True*	*Don't Know*	*Mostly False*	*Definitely False*	
a.	I seem to get sick a little easier than other people.	1	2	3	4	5	I11a
b.	I am as healthy as anybody I know.	1	2	3	4	5	I11b
c.	I expect my health to get worse.	1	2	3	4	5	I11c
d.	My health is excellent.	1	2	3	4	5	I11d

LIFE EVENTS SECTION

1. Have any of the following events happened to you in <u>the past six months</u>?   D1(a-m)
   (<u>Check All That Apply</u>)

a. ☐ You retired, were fired, or laid off from work.

b. ☐ You were unemployed and looking for work.

c. ☐ Your spouse retired, was fired, or laid off from work.

d ☐ Your spouse was unemployed and looking for work.

e. ☐ You had problems with the police or court.

f. ☐ You got into serious financial difficulties.

g. ☐ A close family member was seriously ill or injured.

h. ☐ You had a marital separation or divorce.

i. ☐ You had serious troubles with relatives or close friends.

j. ☐ Your spouse had troubles or difficulties with relatives or close friends.

k. ☐ A close family member died.

l. ☐ A close friend or relative died.

m. ☐ You were seriously ill or injured.

This last section deals with your views of cancer prevention and treatment.

1. To what extent do you agree with the following statements?

		Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree	
a.	In the next year, there will be dramatic breakthroughs in the <u>prevention</u> of breast and/or ovarian cancer.	1	2	3	4	5	N7a
b.	In the next year, there will be dramatic breakthroughs in the <u>treatment</u> of breast and/or ovarian cancer.	1	2	3	4	5	N7b
c.	In the next year, the length of <u>survival</u> after diagnosis of breast cancer will increase.	1	2	3	4	5	N7c
d.	In the next year, the length of <u>survival</u> after diagnosis of ovarian cancer will increase.	1	2	3	4	5	N7d

		Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree	
e.	In the next 5 years, there will be dramatic breakthroughs in the <u>prevention</u> of breast and/or ovarian cancer.	1	2	3	4	5	N7e
f.	In the next 5 years, there will be dramatic breakthroughs in the <u>treatment</u> of breast and/or ovarian cancer.	1	2	3	4	5	N7f
g.	In the next five years, the length of <u>survival</u> after diagnosis of breast cancer will increase.	1	2	3	4	5	N7g
h.	In the next five years, the length of <u>survival</u> after diagnosis of ovarian cancer will increase.	1	2	3	4	5	N7h
i.	In the future, all women will routinely receive genetic testing for risk of breast and ovarian cancer.	1	2	3	4	5	N7i

Thank You Very Much For Your Participation!

WOMEN'S HEALTH STUDY
Post-Results Questionnaire #3
12 Month Follow-Up

TODAY'S DATE _____   ID _____

POST-RESULTS.3--*12 Month Follow-Up*

First of all, we would like to acknowledge that we are asking many of the same questions that we've asked before. This way we can better understand how your reactions have changed or have stayed the same over time.

__Genetic Testing__

1.   How distressed were you when you received your genetic test results?

Not At All Distressed				Very Distressed
1	2	3	4	5

B69b

2.   Overall, do you regret the decision to obtain your results?

Not At All				Very Much So
1	2	3	4	5

B71a

3.   With your genetic test results, Are you now considering any of the following options? Please circle only one response for each option.

		Done Before Obtaining Results	Definitely Will NOT Do	Probably Will NOT Do	Probably Will Do	Definitely Will Do	Done After Obtaining Results	Does Not Apply to Me	
a.	Prophylactic Oophorectomy (ovaries removed)	0	1	2	3	4	5	-8	B103a
b.	Prophylactic Mastectomy	0	1	2	3	4	5	-8	B103b
c.	Monthly Breast Self-Exams	0	1	2	3	4	5	-8	B103c
d.	Yearly Physical Exams	0	1	2	3	4	5	-8	B103d
e.	Mammograms at least once a year	0	1	2	3	4	5	-8	B103e
f.	Encouraging my relatives to be tested	0	1	2	3	4	5	-8	B103f
g.	Discouraging my relatives from being tested	0	1	2	3	4	5	-8	B103g
h.	Telling some of my relatives what my results were	0	1	2	3	4	5	-8	B103h

4. For each of the following areas of your life, please indicate how much these decisions/plans have been affected by <u>the results of genetic testing</u>?

		Not at all Affected				Very Much Affected	Not Applicable	
a.	Decisions about having children	1	2	3	4	5	-8	B35c
b.	Decisions about forms of birth control	1	2	3	4	5	-8	B36c
c.	Decisions about which steps to take to prevent breast cancer	1	2	3	4	5	-8	B37c
d.	Decisions about work and career	1	2	3	4	5	-8	B38c
e.	Decisions about savings and financial planning	1	2	3	4	5	-8	B39c
f.	Plans for your future	1	2	3	4	5	-8	B40c
g.	Plans for your daughter's future	1	2	3	4	5	-8	B42c

5. On the whole, what effect has testing had on <u>your life</u>?

Very Negative Effect	Somewhat Negative Effect	No Effect	Somewhat Positive Effect	Very Positive Effect	
1	2	3	4	5	N15

6. Think about your everyday <u>family life</u>. What effect would you say getting the genetic test results has had?

Very Negative Effect	Somewhat Negative Effect	No Effect	Somewhat Positive Effect	Very Positive Effect	
1	2	3	4	5	N16

7. What effect has getting your results had on your <u>work</u> in and outside of the home?

Very Negative Effect	Somewhat Negative Effect	No Effect	Somewhat Positive Effect	Very Positive Effect	
1	2	3	4	5	N17

8. What effect has getting your results had on your concerns for your <u>child's/children's future</u>?

Very Negative Effect	Somewhat Negative Effect	No Effect	Somewhat Positive Effect	Very Positive Effect
1	2	3	4	5

N19

9. Has getting these results changed the likelihood that you will have (more) children?

Yes, Will Have Fewer Children	No Change	Yes, Will Have More Children
1	2	3

N22

10. How has getting genetic testing affected your anxiety about the <u>future</u>?

Less Anxiety	No Change	More Anxiety
1	2	3

N18

11. Are there any OTHER areas of your life that testing has affected?

N20

    (1) ☐ Yes   (5) ☐ No

11a. Please List Other Areas of your life Affected by Genetic testing:

N20a

_____

_____

_____

_____

_____

_____

12. How much has getting test results changed your health care decision(s)?

Not At All	A Little	Some	Quite a Bit	Very Much
1	2	3	4	5

N21

12a. If applicable, How have your health care decisions changed?

_____

_____

_____

13. In general, how much has getting genetic results changed your life?

Not At All	A Little	Some	Quite a Bit	Very Much	
1	2	3	4	5	N23

13a. If applicable, How has your life changed?

_____

_____

_____

14. Now, we would like to ask you some questions about worries you may or may not experience.

		Not At All				All The Time	
a.	How often do you worry about developing breast cancer or developing breast cancer again?	1	2	3	4	5	B27
b.	To what extent do these worries interfere with your every day life?	1	2	3	4	5	B28
c.	How often do you worry about developing ovarian cancer or developing ovarian cancer again?	1	2	3	4	5	B110
d.	To what extent do these worries interfere with your every day life?	1	2	3	4	5	B111
e.	How often do you worry about **your relatives** developing breast or ovarian cancer?	1	2	3	4	5	B106
f.	To what extent do these worries interfere with your every day life?	1	2	3	4	5	B107
g.	How often do you worry about **your relatives** having an altered gene associated with risk for breast and ovarian cancer?	1	2	3	4	5	B108
h.	To what extent do these worries interfere with your every day life?	1	2	3	4	5	B109

Coping Section

1. How confident are you that **you** are coping effectively after getting your genetic test results?

Not At All Confident						Very Confident
1	2	3	4	5	6	7

B48e

2. How confident are you that **your family members** are coping effectively with the results of your genetic testing?

Not At All Confident						Very Confident
1	2	3	4	5	6	7

B48f

3. Below is a list of comments made by people after they have received their genetic test results. When you read each comment, think about your thoughts and feelings toward the test results. Please indicate how often each of the comments has been true for you since you received your test results, with the choices of *Not at All, Rarely, Sometimes,* and *Often.*

"IT" in the following questions refers to "RECEIVING YOUR TEST RESULTS")		Not at All	Rarely	Sometimes	Often	
a.	I thought about it when I didn't mean to.	0	1	3	5	B116a
b.	I avoided letting myself get upset when I thought about it or was reminded of it.	0	1	3	5	B116b
c.	I tried to remove it from memory.	0	1	3	5	B116c
d.	I had trouble falling asleep or staying asleep, because of pictures or thoughts about it that came into my mind.	0	1	3	5	B116d
e.	I had waves of strong feelings about it.	0	1	3	5	B116e
f.	I had dreams about it.	0	1	3	5	B116f
g.	I stayed away from reminders of it.	0	1	3	5	B116g
h.	I felt as if it hadn't happened or it wasn't real.	0	1	3	5	B116h
i.	I tried not to talk about it.	0	1	3	5	B116i
j.	Pictures about it popped into my mind.	0	1	3	5	B116j

"IT" in the following questions refers to "RECEIVING YOUR TEST RESULTS")	Not at All	Rarely	Sometimes	Often	
k.	Other things kept making me think about it.	0	1	3	5	B116k
l.	I was aware that I still had a lot of feelings about it, but I didn't deal with them	0	1	3	5	B116l
m.	I tried not to think about it.	0	1	3	5	B116m
n.	Any reminder brought back feelings about it.	0	1	3	5	B116n
o.	My feelings about it were kind of numb.	0	1	3	5	B116o

Family Events

We would like to ask you if there were any recent events in your family related to cancer or risk for cancer.

1. To your knowledge, have any of your family members received genetic test results **in the past 6 months**? What is their relationship to you? Do you know if a mutation was found? Positive or Negative?

    (1) ⎵ Yes   (5) ⎵ No (Skip to Next Question)

Total # of Family Members who Received Results: _____   N8t

	Relationship to You:	Positive Mutation Found	Negative No Mutation Found	Don't Know	
a.		1	0	-9	N8a
b.		1	0	-9	N8b
c.		1	0	-9	N8c

2. Have any of your family members declined receiving test results **in the past 6 months**?

    (1) ⎵ Yes   (5) ⎵ No (Skip to Next Question)

Total # of Family Members who Declined Results: _____   N9t

	Relationship to You:	
a.		N9a
b.		N9b
c.		N9c

3.   Have any family members received a new diagnosis of cancer **in the past 6 months?**

(1) ☐ Yes   (5) ☐ No (Skip to Next Question)

Total # of Family Members who had a New Diagnosis of cancer : _____   N10t

	Relationship to You:	
a.		N10a
b.		N10b
c.		N10c

4.   Have any family members had prophylactic surgery **in the past 6 months?**

(1) ☐ Yes   (5) ☐ No (Skip to Next Question)

Total # of Family Members who had Prophylactic Surgery: _____   N11

	Relationship to You:	Prophylactic Procedure:	
a.			N11a
b.			N11b
c.			N11c

5.   Have any family members had any other things happen related to cancer or risk of cancer **in the past 6 months?** [such as treatment, surgery, or death?]

(1) ☐ Yes   (5) ☐ No (Skip to Next Question)

Total # Family Members with a Cancer Related Event: _____   N12

	Relationship to You:	Event related to cancer:	
a.			N12a
b.			N12b
c.			N12c

6.   In the last six months, How often have you discussed your genetic results with each of the following family members?

		Not at All	Rarely	Sometimes	Often	A Lot	Not Applicable	
a.	Spouse	1	2	3	4	5	-8	N31a
b.	Daughter	1	2	3	4	5	-8	N31b
c.	Son	1	2	3	4	5	-8	N31c

		Not at All	Rarely	Sometimes	Often	A Lot	Not Applicable	
d.	Mother	1	2	3	4	5	-8	N31d
e.	Grandmother	1	2	3	4	5	-8	N31e
f.	Sister	1	2	3	4	5	-8	N31f
g.	Aunt	1	2	3	4	5	-8	N31g
h.	Cousin	1	2	3	4	5	-8	N31h

Health Section

1. How often do you usually get a mammogram? B32a
   - 1 ☐ Never (I have never had a mammogram).
   - 2 ☐ Less than Once a Year
   - 3 ☐ Once a Year
   - 4 ☐ More than Once a Year
   - -8 ☐ Does Not Apply because of surgery

2. How often do you perform self-examination of your breasts? B33a
   - 1 ☐ Never or rarely
   - 2 ☐ Less than Once a Month
   - 3 ☐ Monthly
   - 4 ☐ More than Once a Month
   - -8 ☐ Does Not Apply because of surgery

3. How often do you get CA-125 screening for ovarian cancer? B33b
   - 1 ☐ Never (I have never had a CA-125 screening).
   - 2 ☐ Less than Once a Year
   - 3 ☐ Once a Year
   - 4 ☐ More than Once a Year
   - -8 ☐ Does Not Apply because of surgery

4. How often do you get ultrasound screening for ovarian cancer? B33c
   - 1 ☐ Never (I have never had an ovarian ultrasound for cancer screening).
   - 2 ☐ Less than Once a Year
   - 3 ☐ Once a Year
   - 4 ☐ More than Once a Year
   - -8 ☐ Does Not Apply because of surgery

5. Has knowing your genetic results affected your **motivation** to perform breast self examination as **frequently** as needed?

Decreased Motivation		No Effect		Increased Motivation	Does Not Apply because of surgery	
1	2	3	4	5	-8	B34d

6. Has knowing your genetic results affected your **confidence** that you will perform breast self examination as **frequently** as needed?

Decreased Confidence		No Effect		Increased Confidence	Does Not Apply because of surgery	B34e
1	2	3	4	5	-8	

7. Has knowing your genetic results affected your **confidence** that you will perform breast self examination as **carefully and competently** as needed?

Decreased Confidence		No Effect		Increased Confidence	Does Not Apply because of surgery	B34f
1	2	3	4	5	-8	

Symptoms of Strain Section

Listed below are some symptoms of strain that people sometimes have. Please read Each One Carefully And Circle The Answer Which Best Reflects How Much That Symptom Has BOTHERED you during the PAST THREE MONTHS. Please use the following scale: 1=Not at all, 2=A little, 3=Quite a bit, and 4=Extremely.

		Not at all	_A little_	_Quite a bit_	_Extremely_	
1.	Suddenly scared for no reason	1	2	3	4	K1.
2.	Feeling fearful	1	2	3	4	K2.
3.	Faintness, dizziness, or weakness	1	2	3	4	K3.
4.	Nervousness or shakiness inside	1	2	3	4	K4.
5.	Heart pounding or racing	1	2	3	4	K5.
6.	Trembling	1	2	3	4	K6.
7.	Feeling tense or keyed up	1	2	3	4	K7.
8.	Headaches	1	2	3	4	K8.
9.	Spells of terror or panic	1	2	3	4	K9.
10.	Feeling restless, can't sit still	1	2	3	4	K10.
11.	Feeling low in energy--slowed down	1	2	3	4	K11.
12.	Blaming yourself for things	1	2	3	4	K12.
13.	Crying easily	1	2	3	4	K13.
14.	Loss of sexual interest or pleasure	1	2	3	4	K14.

		Not at all	A little	Quite a bit	Extremely	
15.	Poor appetite	1	2	3	4	K15.
16.	Difficulty falling asleep, staying asleep	1	2	3	4	K16.
17.	Feeling hopeless about the future	1	2	3	4	K17.
18.	Feeling blue	1	2	3	4	K18.
19.	Feeling lonely	1	2	3	4	K19.
20.	Feeling trapped or caught	1	2	3	4	K20.
21.	Worrying too much about things	1	2	3	4	K21.
22.	Feeling no interest in things	1	2	3	4	K22.
23.	Thoughts of ending your life	1	2	3	4	K23.
24.	Feeling everything is an effort	1	2	3	4	K24.
25.	Feelings of worthlessness	1	2	3	4	K25.

26.   To what extent are these current symptoms a result of getting genetic testing?

Not At All	A Little	Some	Quite a Bit	Very Much	
1	2	3	4	5	K26

Your Participation has been very much appreciated. Your contribution to the study of genetic testing for breast and ovarian cancer has been great. This is the last questionnaire for our study. A sincere thank you for hanging in with us over the past few years!

-Women's Health Study Staff

B.VI. Long-Term Follow-Up Questionnaires (Male & Female)

□□□-□□□

UNIVERSITY OF PENNSYLVANIA MEDICAL CENTER

University of Michigan Medical Center

LONG TERM FOLLOW-UP STUDY
Questionnaire

LONGITUDINAL ASSESSMENT--*for Men*

This is a follow up questionnaire from a joint project being conducted by the University of Michigan Medical Center and the University of Pennsylvania Cancer Center. It is for people who have received results of genetic testing for an altered gene associated with risk of breast and ovarian cancer. As genetic testing becomes more routine, it is important for us to know how this information affects people's quality of life and future health care decisions. Thank you very much for your participation!

Genetic Testing Section

1. When did you receive your results of genetic testing?   **B101.**

    (Month/Year) _____

2. Did you encourage your relatives to be tested for BRCA1/BRCA2 before you obtained   **B102h.**
    your results?

    (1) ☐ Yes   (5) ☐ No

3. Did you discourage your relatives from being tested for BRCA1/BRCA2 before you   **B102i.**
    obtained your results?

    (1) ☐ Yes   (5) ☐ No

4. Please rate the extent to which each of the following were your reasons for getting your results.

		Not at all				Very Much So	
a.	To plan for the future.	1	2	3	4	5	B16b1.
b.	To reduce the uncertainty.	1	2	3	4	5	B16b2.
c.	To make decisions about family planning.	1	2	3	4	5	B16b5.
d.	To find out the risk that may be transmitted to my children.	1	2	3	4	5	B16b6.
e.	Family members wanted me to get testing.	1	2	3	4	5	B16b7.
f.	Other (describe)_____	1	2	3	4	5	B16b8.

5. Before getting your test results, how distressing had it been for you to know that your family may be at increased risk for breast cancer because of your family history?

Not At All Distressing				Very Distressing
1	2	3	4	5

B66b.

6. How distressed **did you expect to be** when you were told you have an altered BRCA1/BRCA2 gene (before you received results)?

Not At All Distressed				Very Distressed
1	2	3	4	5

B68b.

7. How distressed were you when you were told that you had an altered BRCA1 (or BRCA2) gene?

Not At All Distressed				Very Distressed
1	2	3	4	5

B69b.

8. Overall, do you regret the decision to obtain your results?

Not At All				Very Much So
1	2	3	4	5

B71a.

9. When you received your results, what were your immediate reactions?

		Not At All				Very Much So	
a.	I felt relieved about being more certain.	1	2	3	4	5	B82a.
b.	I felt I had been told what I knew all along.	1	2	3	4	5	B82b.
c.	I did not believe the results.	1	2	3	4	5	B82c.
d.	I felt guilty.	1	2	3	4	5	B82d.
e.	I was depressed.	1	2	3	4	5	B82e.
f.	I worried about the future.	1	2	3	4	5	B82f.

		Not At All				Very Much So	
g.	I thought I would just fall apart emotionally.	1	2	3	4	5	B82g.
h.	I felt anxious.	1	2	3	4	5	B82h.
i.	I felt angry.	1	2	3	4	5	B82i.

10. We are interested in things that people do after being notified of their test results. *After* obtaining your results, which options are you now considering? Please circle one response.

		Definitely Will NOT Do	Probably Will NOT Do	Probably Will Do	Definitely Will Do	Done After Obtaining Results	Does Not Apply to Me	
a.	Encouraging my relatives to be tested	1	2	3	4	5	-9	B103f.
b.	Discouraging my relatives from being tested	1	2	3	4	5	-9	B103g.
c.	Telling some of my relatives what my results were	1	2	3	4	5	-9	B103h.
d.	Not telling some of my relatives what my results were	1	2	3	4	5	-9	B103i.

11. Do you feel you were adequately informed about the benefits and drawbacks of genetic testing for risk of breast cancer **before getting your results**?

Not At All						Very Much
1	2	3	4	5	6	7

B44a.

12. Do you feel you are adequately informed about what it would mean for your children that you have an altered BRCA1/BRCA2 gene?

Not At All						Very Much
1	2	3	4	5	6	7

B47a.

13. How confident are you that **you** will cope effectively with the finding that you have an altered BRCA1/BRCA2 gene?

Not At All						Very Much
1	2	3	4	5	6	7

B48e.

14. How confident are you that **your family members** will cope effectively with the finding that you have an altered BRCA1/BRCA2 gene?

Not At All						Very Much
1	2	3	4	5	6	7

B48f.

15. How much have you discussed results of your genetic testing with female relatives **other than** your spouse/partner?

B105a.

Not at All	Very Little	Some	A Lot
1	2	3	4

16. When you have these discussions, who generally initiates them?

B105b.

You	Your Relatives	Equally
1	2	3

17. How satisfied are you with these discussions?

B105c.

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

4

Personal Attitudes Section

1. For each of these statements, please indicate the extent to which you agree or disagree by circling the appropriate number. There are no right or wrong answers. We are only interested in your opinions.

		Strongly Disagree				Strongly Agree	
a.	If you don't have your health, you don't have anything.	1	2	3	4	5	L5a.
b.	There are many things I care about more than my health.	1	2	3	4	5	L5b.
c.	Good health is of only minor importance in a happy life.	1	2	3	4	5.	L5c.
d.	There is nothing more important than good health.	1	2	3	4	5	L5d.
e.	In uncertain times, I usually expect the best.	1	2	3	4	5	E1.
f.	It's easy for me to relax.	1	2	3	4	5	E2.
g.	If something can go wrong for me, it will.	1	2	3	4	5	E3.
h.	I always look on the bright side of things.	1	2	3	4	5	E4.
i.	I'm always optimistic about my future.	1	2	3	4	5	E5.
j.	I enjoy my friends a lot.	1	2	3	4	5	E6.
k.	It's important for me to keep busy.	1	2	3	4	5	E7.
l.	I hardly ever expect things to go my way.	1	2	3	4	5	E8.
m.	Things never work out the way I want them to.	1	2	3	4	5	E9.
n.	I don't get upset too easily.	1	2	3	4	5	E10.
o.	I'm a believer in the idea that "every cloud has a silver lining."	1	2	3	4	5	E11.
p.	I rarely count on good things happening to me.	1	2	3	4	5	E12.

2. Now, we would like to ask you some questions about your concerns of breast cancer in your family?

		Not At All				All The Time	
C1.	How often do you worry about **your relatives** developing breast cancer?	1	2	3	4	5	B32.
C2.	To what extent do these worries interfere with your every day life?	1	2	3	4	5	B33.
C3.	How often do you worry about **your relatives** having an altered gene associated with risk for breast cancer?	1	2	3	4	5	B34.
C4.	To what extent do these worries about interfere with your every day life?	1	2	3	4	5	B35.

Coping Section

1. Sometimes people can find unexpected benefits in difficulties. We are interested in the ways in which you might have made positive use of your knowing that you have an altered gene which increases the risk of breast cancer. For each of the statements below, indicate the degree to which your life has been affected positively by your finding you have an altered gene.

		Not At All	A Very Small Degree	A Small Degree	A Moderate Degree	A Great Degree	A Very Great Degree	
a.	My priorities about what is important in life.	1	2	3	4	5	6	L6a.
b.	I'm more likely to try to change things which need changing.	1	2	3	4	5	6	L6b.
c.	An appreciation for the value of my own life.	1	2	3	4	5	6	L6c.
d.	A feeling of self-reliance.	1	2	3	4	5	6	L6d.
e.	A better understanding of spiritual matters.	1	2	3	4	5	6	L6e.
f.	Knowing that I can count on people in times of troubles.	1	2	3	4	5	6	L6f.
g.	A sense of closeness with others.	1	2	3	4	5	6	L6g.
h.	Knowing I can handle difficulties.	1	2	3	4	5	6	L6h.
i.	A willingness to express my emotions.	1	2	3	4	5	6	L6i.

		Not At All	A Very Small Degree	A Small Degree	A Moderate Degree	A Great Degree	A Very Great Degree	
j.	Being able to accept the way things work out.	1	2	3	4	5	6	L6j.
k.	Appreciating each day.	1	2	3	4	5	6	L6k.
l.	Having compassion for others.	1	2	3	4	5	6	L6l.
m.	I'm able to do better things with my life.	1	2	3	4	5	6	L6m.
n.	New opportunities are available which wouldn't have been otherwise.	1	2	3	4	5	6	L6n.

2. This set of questions deals with ways you've been coping with the stress in your life that goes with knowing you have an altered gene associated with increased risk for breast cancer. Obviously, different people deal with things in different ways, but we are interested in how you've tried to deal with it. Each item says something about a particular way of coping. We want to know *to what extent* you've been doing what the item says, how *much* or how *frequently*. Don't answer on the basis of whether it seems to be working, but just whether or not you're doing it. Use these response choices below and try not to let one answer influence another. Make your answers as true FOR YOU as you can.

		I haven't been doing this at all	I've been doing this a little bit	I've been doing this some	I've been doing this a lot	
a.	I've been turning to work or other activities to take my mind off things.	1	2	3	4	L7a.
b.	I've been concentrating my efforts on doing something about my situation.	1	2	3	4	L7b.
c.	I've been saying to myself "this isn't possible."	1	2	3	4	L7c.
d.	I've been using alcohol or other drugs to make myself feel better.	1	2	3	4	L7d.
e.	I've been getting emotional support from others.	1	2	3	4	L7e.
f.	I've been giving up trying to deal with it.	1	2	3	4	L7f.
g.	I've been taking action to try to make the situation better.	1	2	3	4	L7g.
h.	I've been refusing to believe that it is possible that I have an altered gene.	1	2	3	4	L7h.

		I haven't been doing this at all	I've been doing this a little bit	I've been doing this some	I've been doing this a lot	
i.	I've been saying things to let my unpleasant feelings escape.	1	2	3	4	L7i.
j.	I've been using alcohol or other drugs to help me get through it.	1	2	3	4	L7j.
k.	I've been trying to see it in a different light, to make it seem more positive.	1	2	3	4	L7k.
l.	I've been trying to come up with a strategy about what to do.	1	2	3	4	L7l.
m.	I've been getting comfort and understanding from someone.	1	2	3	4	L7m.
n.	I've been giving up the attempt to cope.	1	2	3	4	L7n.
o.	I've been accepting the possibility that I might have an altered gene.	1	2	3	4	L7o.
p.	I've been expressing my negative feelings.	1	2	3	4	L7p.
q.	I've been trying to find comfort in my religion or spiritual beliefs.	1	2	3	4	L7q.
r.	I've been learning to live with the possibility that I have an altered gene.	1	2	3	4	L7r.
s.	I've been thinking hard about what steps to take.	1	2	3	4	L7s.
t.	I've been praying or meditating.	1	2	3	4	L7t.
u.	I've been making fun of the situation.	1	2	3	4	L7u.

The following items are to be answered only by those women who are married or living with a partner.

☐ If not married or living with a partner skip to the Mood section, directly below.

		I haven't been doing this at all	*I've been doing this a little bit*	*I've been doing this some*	*I've been doing this a lot*	
v.	I've been denying or hiding my anger around my spouse/partner.	1	2	3	4	Lv.
w.	I've been denying or hiding my worries around my spouse/partner.	1	2	3	4	Lw.
x.	I've been avoiding talking about my problems around my spouse/partner.	1	2	3	4	Lx.
y.	I've acted more positive around my spouse/partner than I feel.	1	2	3	4	Ly.

MOOD SECTION

1. In **the past 6 months**, have you had two weeks or more when nearly every day you felt sad, blue, or depressed <u>or</u> in which you lost all interest in things like work or hobbies or things you usually liked to do for fun?   (1) ☐ Yes   (5) ☐ No (Skip to Question 2)   **I12.**

   1a. If there was such a two-week period in **the past 6 months**, did your work or relationships suffer?   **I12a.**
   (1) ☐ Yes   (5) ☐ No

   1b. If there was such a two-week period in **the past 6 months**, did you get counseling or psychotherapy?   **I12b.**
   (1) ☐ Yes   (5) ☐ No

   1c. If there was such a two-week period in **the past 6 months**, did you get medication for this condition?   **I12c.**
   (1) ☐ Yes   (5) ☐ No

2. Have you **ever in your lifetime** had two weeks or more when nearly every day you felt sad, blue, or depressed <u>or</u> in which you lost all interest in things like work or hobbies or things you usually liked to do for fun?   (1) ☐ Yes   (5) ☐ No (Skip to Question 3, next page)   **I14**

   2a. If there was such a two-week period, did your work or relationships suffer?   **I14a.**
   (1) ☐ Yes   (5) ☐ No

   2b. If there was such a two-week period, did you get counseling or psychotherapy?   **I14b.**
   (1) ☐ Yes   (5) ☐ No

   2c. If there was such a two-week period, did you get medication for this condition?   **I14c.**
   (1) ☐ Yes   (5) ☐ No

3. Are you **currently** receiving counseling, psychotherapy or medication for depression or emotional problems?   **I13.**
   (1) ☐ Yes   (5) ☐ No

9

Symptoms of Strain Section

LISTED BELOW ARE SOME SYMPTOMS OF STRAIN THAT PEOPLE SOMETIMES HAVE. *Please Read Each One Carefully And Check The Answer Which Best Reflects How Much That Symptom Has Bothered You During the* ___Past Three Months___.

		Not at all	A little	Quite a bit	Extremely	
1.	Suddenly scared for no reason	1	2	3	4	K1.
2.	Feeling fearful	1	2	3	4	K2.
3.	Faintness, dizziness, or weakness	1	2	3	4	K3.
4.	Nervousness or shakiness inside	1	2	3	4	K4.
5.	Heart pounding or racing	1	2	3	4	K5.
6.	Trembling	1	2	3	4	K6.
7.	Feeling tense or keyed up	1	2	3	4	K7.
8.	Headaches	1	2	3	4	K8.
9.	Spells of terror or panic	1	2	3	4	K9.
10.	Feeling restless, can't sit still	1	2	3	4	K10.
11.	Feeling low in energy--slowed down	1	2	3	4	K11.
12.	Blaming yourself for things	1	2	3	4	K12.
13.	Crying easily	1	2	3	4	K13.
14.	Loss of sexual interest or pleasure	1	2	3	4	K14.
15.	Poor appetite	1	2	3	4	K15.
16.	Difficulty falling asleep, staying asleep	1	2	3	4	K16.
17.	Feeling hopeless about the future	1	2	3	4	K17.
18.	Feeling blue	1	2	3	4	K18.
19.	Feeling lonely	1	2	3	4	K19.
20.	Feeling trapped or caught	1	2	3	4	K20.
21.	Worrying too much about things	1	2	3	4	K21.
22.	Feeling no interest in things	1	2	3	4	K22.
23.	Thoughts of ending your life	1	2	3	4	K23.
24.	Feeling everything is an effort	1	2	3	4	K24.
25.	Feelings of worthlessness	1	2	3	4	K25.

Relationships Section

1. Is there anyone in your life with whom you can share your most private feelings without holding back?   C21.

  (1) ☐ Yes   (5) ☐ No

Please complete the following questions only if you are <u>married or living with a partner</u>. If you are not married or living with a partner, please check the box and skip to Background Information Section on page 14.

Not married or living with a partner ☐

2. If married, can you share your most private feelings with your spouse without holding back?   C21a.

  (1) ☐ Yes   (5) ☐ No

3. If married, is there anyone besides your spouse with whom you can share your most private feelings without holding back?   C21b.

  (1) ☐ Yes   (5) ☐ No

First, we would like to ask you some questions about your spouse/partner's involvement in your health care.

4. Did your spouse/partner attend individual, family or group sessions to become informed about your risk for breast cancer and what can be done?   H36.

  Yes (1) ☐   No (5) ☐

5. How much contact did your spouse/partner have with medical personnel concerning your family's risk for breast cancer and what can be done about it?   H37.

  | Very Little or None | | | | | | A Lot |
  | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

6. Do you feel your spouse/partner is adequately informed concerning your family's risk for breast cancer and what can be done about it?   H38.

  | Not at All | | | | | | Very Much |
  | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

11

7. To what extent are you satisfied with your spouse's/partner's involvement in your health care?   H39.

      Not at All   Very Much
        1   2   3   4   5   6   7

8. How much have you discussed results of your genetic testing with your spouse/partner?   B104a.

Not at All	Very Little	Some	A Lot
1	2	3	4

9. When you have these discussions, who generally initiates them?   B104b.

You	Your Spouse	Equally
1	2	3

10. How satisfied are you with these discussions?   B104c.

Not at All	A Little	Somewhat	A Great Deal
1	2	3	4

Second, we would like to ask you some questions about your marriage.

11. Most people have disagreements in their relationships. Please indicate by circling the number that represents the extent of agreement or disagreement experienced between you and your spouse/partner **DURING THE PAST MONTH**.

		Always Agree	Almost Always Agree	Occa-sionally Disagree	Fre-quently Disagree	Almost Always Disagree	Always Disagree	
a.	Religious matters	1	2	3	4	5	6	H3.
b.	Demonstration of affection	1	2	3	4	5	6	H4.
c.	Sex relations	1	2	3	4	5	6	H6.
d.	Conventionality (correct or proper behavior)	1	2	3	4	5	6	H7.
e.	Making major decisions	1	2	3	4	5	6	H12.
f.	Career decisions	1	2	3	4	5	6	H15.

		All of the time	Most of the time	More often than most	Occa-sionally	Rarely	Never	
12.	How often do you discuss or have you considered divorce, separation, or terminating your relationship?	1	2	3	4	5	6	H16.
13.	Do you ever regret that you married (or lived together)?	1	2	3	4	5	6	H20.
14.	How often do you and your partner quarrel?	1	2	3	4	5	6	H21.
15.	How often do you and your spouse/partner "get on each other's nerves?"	1	2	3	4	5	6	H22.

		All of Them	Most of Them	Some of Them	Very few of Them	None of Them	
16.	Do you and your spouse/partner engage in outside interests together?	1	2	3	4	5	H24.

How often would you say the following events occur between you and your spouse/partner?

		Never	Less than once a month	About twice a month	About twice a week	Once a day	More Often	
17.	Have a stimulating exchange of ideas	1	2	3	4	5	6	H25.
18.	Calmly discuss something	1	2	3	4	5	6	H27.
19.	Work together on a project	1	2	3	4	5	6	H28.

20. Considering **only the positive feelings** you have towards your spouse/partner, and **ignoring the negative ones**, please rate how positive these feelings are: H33.

Not At All Positive								Extremely Positive	
1	2	3	4	5	6	7	8	9	10

21. Considering **only the negative feelings** you have towards your spouse/partner, and **ignoring the positive ones**, please rate how negative these feelings are:

H34.

Not At All Negative									Extremely Negative
1	2	3	4	5	6	7	8	9	10

Background Information Section

1. Date of Birth ____Month _____Day _____Year

A1.

2. Ethnic Background:

White	☐ 1	Black	☐ 4
Hispanic	☐ 2	Asian	☐ 5
Native American	☐ 3	Other	☐ 6

A2.

3. Religion:

Catholic	☐ 1	Protestant	☐ 4
Jewish	☐ 2	Buddhist	☐ 5
Muslim	☐ 3	Other	☐ 6
		None	☐ 7

A3.

3a. How often do you attend religious services?

A3a.

☐ 1 Less Than Once a Month   ☐ 5 A Few Times A Month or More

3b. How important are religious and spiritual beliefs in your life?

A3b.

Not at All				Very Important
1	2	3	4	5

4. Are you currently (**please check one**)?

A4.

1 ☐ Single   4 ☐ Separated
2 ☐ Married   5 ☐ Divorced
3 ☐ Not married, but living in a steady,   6 ☐ Widowed
    marriage-like relationship

5. If you **are** currently married, what was the date of your current marriage?

A5.

(Month/ Year) _____

5a. Is this your first marriage?   (1) ☐ Yes   (5) ☐ No

A5a.

6. How many children do you have? _____

A6.

6a. Number of children living at home?   _____

A6a.

6b. Number who are under age 6?   _____

A6b.

6c. Number of Daughters?   _____

A6c.

14

7. Do you plan to have more children? (1) ☐ Yes   (5) ☐ No   (3) ☐ Undecided   A12.

    7a. If **yes**, how many more children? _____   A12a.

8. Are you currently working for pay outside the home?   A7.

    (1) ☐ Yes   (5) ☐ No

9. If **yes**, about how many hours per week are you working for pay?   A8.

Less than 10   10-20   21-30   31-40   41 or more
    ☐   ☐   ☐   ☐   ☐
   (1)   (2)   (3)   (4)   (5)

10. What is the highest level of education you have completed? (**Please Check one**)   A9.

    1 ☐   Less than 9th grade   5 ☐   Completed college
    2 ☐   Dropped out of high school   6 ☐   Some graduate or professional training
    3 ☐   Completed high school   7 ☐   Completed graduate or professional training
    4 ☐   Some college

The following two questions are optional, but we hope that you will provide this information.

11. What is your household's total income? (**Please Check one**)   A10.

    (1) ☐   Less than $10,000   (4) ☐ $30,000 to $39,999   (7) ☐ $60,000 to $69,999
    (2) ☐ $10,000 to $19,999   (5) ☐ $40,000 to $49,999   (8) ☐   Greater than $69,999
    (3) ☐ $20,000 to $29,999   (6) ☐ $50,000 to $59,999

12. How many people (adults and children) does this income support? _____   A11.

Thank You Very Much For Your Participation!

B.VII. Spouse/Sibling Questionnaires

Spouse Baseline Questionnaire
Spouse 8-Month Post-Results Questionnaire
Sibling Questionnaire
Sibling Post-Results Questionnaire

UNIVERSITY OF PENNSYLVANIA MEDICAL CENTER

University of Michigan Medical Center

WOMEN'S HEALTH STUDY
Spouse/Partner Questionnaire

Today's Date _____

BACKGROUND DATA SECTION

1. Date of Birth _____ Month _____ Day _____ Year   .   A1.

2. Ethnic Background: White   ☐ 1   Black   ☐ 4   A2.
                        Hispanic   ☐ 2   Asian   ☐ 5
                        Native American ☐ 3 Other   ☐ 6

3. Religion: Catholic   ☐ 1   Protestant ☐ 4   A3.
                        Jewish   ☐ 2   Buddhist   ☐ 5
                        Muslim   ☐ 3   Other   ☐ 6
                                            None   ☐ 7

   3a. How often do you attend religious services?   A3a.
        ☐ 1 Less Than Once a Month   ☐ 5 A Few Times A Month or More

   3b. How important are religious and spiritual beliefs in your life?   A3b.
        Not at All   Very Important
          1   2   3   4   5

4. Are you currently working for pay outside the home?   Yes ☐ 1   No ☐ 5   A7.

5. If **yes**, about how many hours per week are you working for pay?   A8.

   Less than 10   10-20   21-30   31-40   41 or more
      ☐   ☐   ☐   ☐   ☐
      (1)   (2)   (3)   (4)   (5)

6. What is the highest level of education you have completed? **(Check one)** A9.

   1 ☐ Less than 9th grade   5 ☐ Completed college
   2 ☐ Dropped out of high school   6 ☐ Some graduate or professional training
   3 ☐ Completed high school   7 ☐ Completed graduate or professional training
   4 ☐ Some college

The following two questions are optional, but we hope that you will provide this information.
Please check the appropriate box. **(Check one)**

7. What is your household's total income? **(Check one)**   A10.
   (1) ☐ Less than $10,000   (4) ☐ $30,000 to $39,999   (7) ☐ $60,000 to $69,999
   (2) ☐ $10,000 to $19,999   (5) ☐ $40,000 to $49,999   (8) ☐ Greater than $69,999
   (3) ☐ $20,000 to $29,999   (6) ☐ $50,000 to $59,999

8. How many people (adults and children) does this income support?_____ A11.

1

PERSONAL ATTITUDES SECTION

1. For each of these statements, please indicate the extent to which you agree or disagree by circling the appropriate number. There are no right or wrong answers. We are only interested in your opinions.

		Strongly Disagree				Strongly Agree	
a.	If you don't have your health, you don't have anything.	1	2	3	4	5	L5a.
b.	There are many things I care about more than my health.	1	2	3	4	5	L5b.
c.	Good health is of only minor importance in a happy life.	1	2	3	4	5	L5c.
d.	There is nothing more important than good health.	1	2	3	4	5	L5d.
e.	In uncertain times, I usually expect the best.	1	2	3	4	5	E1.
f.	It's easy for me to relax.	1	2	3	4	5	E2.
g.	If something can go wrong for me, it will.	1	2	3	4	5	E3.
h.	I always look on the bright side of things.	1	2	3	4	5	E4.
i.	I'm always optimistic about my future.	1	2	3	4	5	E5.
j.	I enjoy my friends a lot.	1	2	3	4	5	E6.
k.	It's important for me to keep busy.	1	2	3	4	5	E7.
l.	I hardly ever expect things to go my way.	1	2	3	4	5	E8.
m.	Things never work out the way I want them to.	1	2	3	4	5	E9.
n.	I don't get upset too easily.	1	2	3	4	5	E10.
o.	I'm a believer in the idea that "every cloud has a silver lining."	1	2	3	4	5	E11.
p.	I rarely count on good things happening to me.	1	2	3	4	5	E12.

HEALTH SECTION

The following questions concern your wife/partner's risk of developing breast cancer again and of her having the altered gene which has been found to be associated with increased risk for breast cancer. As you may know, breast cancer runs in certain families. In some of these families, persons who develop cancer have an altered version of a gene, BRCA1. Some family members will inherit the gene and others will not.

		Not At All				All The Time	
1.	How often do you worry about your wife/partner again developing breast cancer?	1	2	3	4	5	B27.
2.	To what extent do these worries interfere with your every day life?	1	2	3	4	5	B28.
3.	How often do you worry about your wife/partner having the altered gene associated with risk for breast cancer?	1	2	3	4	5	B29.
4.	To what extent do worries about your wife/partner having this altered gene interfere with your every day life?	1	2	3	4	5	B30.
5.	How often do you worry about developing cancer yourself?	1	2	3	4	5	B31.

6. How likely do you think your wife/partner is to develop breast cancer again in **the near future**? **(Please circle one).**   B9.

     0%   10%   20%   30%   40%   50%   60%   70%   80%   90%   100%

7. Overall, what do you believe your wife/partner's risk is of developing breast cancer again **at some point in her lifetime**?   B10.

     0%   10%   20%   30%   40%   50%   60%   70%   80%   90%   100%

8. Overall, what do you believe your wife/partner's risk is of developing some other cancer **unrelated** to breast cancer **at some point in her lifetime**?   B14.

     0%   10%   20%   30%   40%   50%   60%   70%   80%   90%   100%

9. How often does your wife/partner express concern and seek support from you about the risk of breast cancer to herself and women in her family?   B49.

Never	Rarely	Sometimes	Often
1	2	3	4

3

10. How much of a burden is this on you?

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

11. How often do you discuss genetic testing for breast cancer with your wife/partner?

Never	Rarely	Sometimes	Often
1	2	3	4

12. When you have these discussions, who generally initiates them?

You	Your Wife/partner	Equally
1	2	3

13. How satisfied are you with these discussions?

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

14. How often do you and your wife/partner get into a disagreement or conflict over the issue of her getting genetic testing for the risk of breast cancer?

Never	Rarely	Sometimes	Often
1	2	3	4

15. Do you think it is beneficial to have genetic testing for risk of breast cancer available to women?

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

16. Do you want your wife/partner to get genetic testing for risk of breast cancer?

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

17. Overall, how much do you want your opinion to be taken into account in your wife/partner's decision **whether to be tested** for the breast cancer gene?

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

18. Overall, how much do you want your opinion to be taken into account in your wife/partner's decisions **about what to do about her risk** for breast cancer?

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

19. Overall, how important is your opinion in your wife/partner's decision whether to be tested for the altered gene carrying susceptibility to breast cancer?

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

19a. Do you believe your wife has the altered gene that increases the risk of breast cancer?

(1) ☐ Yes   (5) ☐ No

19b. How confident are you in this belief?

Not At All Confident						Very Confident
1	2	3	4	5	6	7

20. Have you attended individual, family or group sessions to become informed about your wife/partner's risk for breast cancer and what can be done?

(1) ☐ Yes   (5) ☐ No

21. How much contact have you had with medical personnel concerning her risk of cancer?

Very Little   A Lot
1   2   3   4   5   6   7

5

22a. Overall, do you feel you are adequately informed concerning your wife/partner's risk for cancer and what can be done about it?

Not at All   Very Much
  1   2   3   4   5   6   7

22b. Do you feel you are adequately informed about your wife/partner's risk for developing breast cancer **again**?

Not at All   Very Much
  1   2   3   4   5   6   7

22c. Do you feel you are adequately informed about the benefits and drawbacks of genetic testing for risk of breast cancer?

Not at All   Very Much
  1   2   3   4   5   6   7

22d. Do you feel you are adequately informed about what your wife/partner could do personally to reduce her risk of breast cancer if she had the altered BRCA1 gene?

Not at All   Very Much
  1   2   3   4   5   6   7

22e. Do you feel you are adequately informed about the benefits and drawbacks of options available to women who have the altered BRCA1 gene?

Not at All   Very Much
  1   2   3   4   5   6   7

22f. Do you feel you are adequately informed about what it would mean for your children if your wife/partner had the altered BRCA1 gene? ☐ **Check here if you do not have children.**
(-8)

Not at All   Very Much
  1   2   3   4   5   6   7

23. How confident are you that your wife/partner:

23a. Will make the best decision about whether to be tested for BRCA1, the altered gene associated with risk of breast cancer?

Not at All   Very Much
  1   2   3   4   5   6   7

23b. Would cope effectively with the finding that she had the altered BRCA1 gene?

Not at All   Very Much
  1   2   3   4   5   6   7

23. (continued) How confident are you that your wife/partner:

23c. Would make the best decision concerning her options if she were found to have the altered BRCA1 gene?

B48c.

Not at All   Very Much
1   2   3   4   5   6   7

23d. Would be able to follow through with her decisions and cope effectively over the long haul if she were found to have the altered BRCA1 gene?

B48d.

Not at All   Very Much
1   2   3   4   5   6   7

24. Please indicate the extent to which you agree or disagree with the following statements using the 1 (strongly disagree) to 5 (strongly agree) scale. Please try to provide your opinion for all of these questions. However, if you feel you simply do not know enough to have an opinion, check the "I don't know" box.

		Strongly Disagree				Strongly Agree	I Don't Know	
a.	Mammography is effective in the early detection of breast cancer in women.	1	2	3	4	5	9	B20a.
b.	Breast cancer that is detected early is curable.	1	2	3	4	5	9	B20b.
c.	Mammography can detect lumps that cannot be felt by a woman or by her doctor.	1	2	3	4	5	9	B20c.
d.	If more women went for breast screening, there would be fewer deaths from breast cancer.	1	2	3	4	5	9	B20d.
e.	If a lump is found in a woman's breast, it is usually too late to do anything about it.	1	2	3	4	5	9	B20f.
f.	There are so many things that could happen to someone's health that it is pointless for a woman to worry about breast cancer.	1	2	3	4	5	9	B20i.
g.	If a woman were found to have breast cancer, the chances of it being cured are high.	1	2	3	4	5	9	B20m.
h.	Once a woman has had effective treatment for breast cancer, she will not get it again.	1	2	3	4	5	9	B20n.
i.	A mastectomy totally eliminates a woman's risk for breast cancer.	1	2	3	4	5	9	B20o.
j.	All women who have the altered version of the BRCA1 gene will get breast cancer.	1	2	3	4	5	9	B20p.
k.	Most of the breast cancer in the United States is due to altered versions of the BRCA1 gene.	1	2	3	4	5	9	B20q.

		Strongly Disagree				Strongly Agree	I Don't Know	
l.	The next decade is going to bring major advances in the detection and treatment of breast cancer.	1	2	3	4	5	9	B20r.
m.	Over the next decade, medical break-through's are going to make breast cancer much less of a threat to women's health.	1	2	3	4	5	9	B20s.

25. If your wife/partner were to take the test and find that she **did not** have the altered version of the BRCA1 gene which is associated with high risk for breast cancer, what would you expect your reactions to be?

		Strongly Disagree				Strongly Agree	
a.	I would feel wonderful.	1	2	3	4	5	B18a.
b.	I would feel I had been told what I knew all along.	1	2	3	4	5	B18b.
c.	I would feel relieved.	1	2	3	4	5	B18c.
d.	I would not believe the results.	1	2	3	4	5	B18d.
e.	I would fall apart emotionally.	1	2	3	4	5	B18e.
f.	I would feel guilty.	1	2	3	4	5	B18f.
g.	I would still feel anxious.	1	2	3	4	5	B18g.
h.	I would feel angry.	1	2	3	4	5	B18h.
i.	I would feel prepared for the future.	1	2	3	4	5	B18i.
j.	I would feel I had done all I needed to do.	1	2	3	4	5	B18j.
k.	I would not feel very differently.	1	2	3	4	5	B18k.

26. If your wife/partner were to take the test and find out that she **had** the altered version of the BRCA1 gene for breast cancer, what would you expect your reactions to be?

		Strongly Disagree				Strongly Agree	
a.	I would feel relieved about being more certain.	1	2	3	4	5	B19a.
b.	I would feel I had been told what I knew all along.	1	2	3	4	5	B19b.
c.	I would not believe the results.	1	2	3	4	5	B19c.
d.	I would feel guilty.	1	2	3	4	5	B19d.
e.	I would feel depressed.	1	2	3	4	5	B19e.

		Strongly Disagree				Strongly Agree	
f.	I would feel worried about the future.	1	2	3	4	5	B19f.
g	I would fall apart emotionally.	1	2	3	4	5	B19g.
h.	I would feel anxious.	1	2	3	4	- 5	B19h.
i.	I would feel angry.	1	2	3	4	5	B19i.
j.	I would not feel very differently.	1	2	3	4	5	B19j.
k.	I would want my daughters to be tested as soon as possible.	1	2	3	4	5	B19k.

27. The following questions concern your involvement in your wife/partner's health care:

		Not at All				Very Often	
a.	To what extent do you go with your wife/partner to her appointments with doctors?	1	2	3	4	5	H35a.
b.	To what extent do you talk with your wife/partner's doctor or other medical personnel about her risk of cancer?	1	2	3	4	5	H35b.
c.	To what extent do you keep track of what your wife/partner needs to do about her risk of cancer?	1	2	3	4	5	H35c.
d.	To what extent do you change your activities to look after your wife/partner?	1	2	3	4	5	H35d.

28. If my wife/partner were tested and found to have the altered BRCA1 gene carrying increased risk of breast cancer, I would want her to manage her risk by relying:

a. Being extra careful about breast self-examination and regular medical examinations.   B64a.

Not at All						Very Much So
1	2	3	4	5	6	7

b. Getting preventive surgery.   B64b.

Not at All						Very Much So
1	2	3	4	5	6	7

29. I do not believe it would be my place to tell my wife/partner my opinion about what she should do about her risk of breast cancer.

Strongly Disagree						Strongly Agree
1	2	3	4	5	6	7

RELATIONSHIPS

1. Is there anyone in your life with whom you can share your most private feelings without holding back?

   (1) ☐ Yes   (5) ☐ No

2. Can you share your most private feelings with your wife/partner without holding back?

   (1) ☐ Yes   (5) ☐ No

3. Is there anyone besides your wife/partner with whom you can share your most private feelings without holding back?

   (1) ☐ Yes   (5) ☐ No

4. Have any of the events listed below happened to you in the past six months?
   (Check All That Apply)

   a. ☐ You retired or were fired or laid off from work.

   b. ☐ You were unemployed and looking for work.

   c. ☐ Your spouse retired or was fired or laid off from work.

   d ☐ Your spouse was unemployed and looking for work.

   e. ☐ You had problems with the police or court.

   f. ☐ You got into serious financial difficulties.

   g. ☐ A close family member was seriously ill or injured.

   h. ☐ You had a marital separation or divorce.

   i. ☐ You had serious troubles with relatives or close friends.

   j. ☐ Your spouse had troubles with relatives or close friends.

   k. ☐ A close family member died.

   l. ☐ A close friend or relative died.

   m. ☐ You were seriously ill or injured.

10

MARRIAGE SECTION

Most people have disagreements in their relationships. Please indicate, using check marks the extent of agreement or disagreement experienced between you and your wife/partner on the following issues **DURING THE PAST MONTH**.

		Always Agree	Almost Always Agree	Occa-sionally Disagree	Fre-quently Disagree	Almost Always Disagree	Always Disagree	
1.	Handling family finances	1	2	3	4	5	6	H1.
2.	Matters of recreation	1	2	3	4	5	6	H2.
3.	Religious matters	1	2	3	4	5	6	H3.
4.	Demonstration of affection	1	2	3	4	5	6	H4.
5.	Friends	1	2	3	4	5	6	H5.
6.	Sex relations	1	2	3	4	5	6	H6.
7.	Conventionality (correct or proper behavior)	1	2	3	4	5	6	H7.
8.	Philosophy of life	1	2	3	4	5	6	H8.
9.	Ways of dealing with parents or in-laws	1	2	3	4	5	6	H9.
10.	Aims, goals, and things believed important	1	2	3	4	5	6	H10.
11.	Amount of time spent together	1	2	3	4	5	6	H11.
12.	Making major decisions	1	2	3	4	5	6	H12.
13.	Household tasks	1	2	3	4	5	6	H13.
14.	Leisure time interests and activities	1	2	3	4	5	6	H14.
15.	Career decisions	1	2	3	4	5	6	H15.

		All of the Time	Most of the Time	More Often than Most	Occasionally	Rarely	Never	
16.	How often do you discuss or have you considered divorce, separation, or terminating your relationship?	1	2	3	4	5	6	H16.
17.	How often do you or your wife/partner leave the house after a fight?	1	2	3	4	5	6	H17.
18.	In general, how often do you think that things between you and your wife/partner are going well?	1	2	3	4	5	6	H18.
19.	Do you confide in your wife/partner?	1	2	3	4	5	6	H19.
20.	Do you ever regret that you married (or lived together)?	1	2	3	4	5	6	H20.
21.	How often do you and your wife/partner quarrel?	1	2	3	4	5	6	H21.
22.	How often do you and your wife/partner "get on each other's nerves?"	1	2	3	4	5	6	H22.

		Every Day	Almost Every Day	Occasionally	Rarely	Never	
23.	Do you kiss your wife/partner?	1	2	3	4	5	H23.

		All of Them	Most of Them	Some of Them	Very few of Them	None of Them	
24.	Do you and your wife/partner engage in outside interests together?	1	2	3	4	5	H24.

33. Considering **only the positive feelings** you have toward your wife/partner, and **ignoring the negative ones**, please rate how positive these feelings are:

Not At All Positive									Extremely Positive
1	2	3	4	5	6	7	8	9	10

34. Considering **only the negative feelings** you have toward your wife/partner, and **ignoring the positive ones**, please rate how negative these feelings are:

Not At All Negative									Extremely Negative
1	2	3	4	5	6	7	8	9	10

CURRENT FAMILY SECTION

Please indicate the extent to which each of the following items describes your current family (your household).

		Strongly Disagree				Strongly Agree	
1.	Planning family activities is difficult because we misunderstand each other.	1	2	3	4	5	M1.
2.	In times of crisis we can turn to each other for support.	1	2	3	4	5	M2.
3.	We cannot talk to each other about the sadness we feel.	1	2	3	4	5.	M3.
4.	Individuals are accepted for who they are.	1	2	3	4	5	M4.
5.	We avoid discussing our fears and concerns.	1	2	3	4	5	M5.
6.	We can express feelings to each other.	1	2	3	4	5	M6.
7.	There are lots of bad feelings in the family.	1	2	3	4	5	M7.
8.	We feel accepted for who we are.	1	2	3	4	5	M8.
9.	Making decisions is a problem for our family.	1	2	3	4	5	M9.
10.	We are able to make decisions about how to solve problems.	1	2	3	4	5	M10.
11.	We don't get along well together.	1	2	3	4	5	M11.
12.	We confide in each other.	1	2	3	4	5	M12.

YOUR HEALTH AND MOOD SECTION

1. In general, would you say your health is:

    (1) ☐ Excellent   (2) ☐ Very Good   (3) ☐ Good   (4) ☐ Fair   (5) ☐ Poor

2. Have you **ever in your life** had two weeks or more when nearly every day you felt sad, blue, or depressed <u>or</u> in which you lost all interest in things like work or hobbies or things you usually liked to do for fun?

    (1) ☐ Yes   (5) ☐ No (Skip to Question 3)

2a. If there was such a two-week period, did your work or relationships suffer?

    (1) ☐ Yes   (5) ☐ No

2b. If there was such a two-week period, did you get counseling or psychotherapy?

    (1) ☐ Yes   (5) ☐ No

2c. If there was such a two-week period, did you get medication for this condition?

    (1) ☐ Yes   (5) ☐ No

3. **In the past 6 months,** have you had two weeks or more when nearly every day you felt sad, blue, or depressed <u>or</u> in which you lost all interest in things like work or hobbies or things you usually liked to do for fun?

    (1) ☐ Yes   (5) ☐ No (Skip to Question 4)

3a. If there was such a two-week period **(in the past 6 months)**, did your work or relationships suffer?

    (1) ☐ Yes   (5) ☐ No

3b. If there was such a two-week period **(in the past 6 months)**, did you get counseling or psychotherapy?

    (1) ☐ Yes   (5) ☐ No

3c. If there was such a two-week period, **(in the past 6 months)** did you get medication for this problem?

    (1) ☐ Yes   (5) ☐ No

4. Are you **currently** receiving counseling, psychotherapy, or medication for depression or emotional problems?

    (1) ☐ Yes   (5) ☐ No

SYMPTOMS OF STRAIN SECTION

LISTED BELOW ARE SOME SYMPTOMS OF STRAIN THAT PEOPLE SOMETIMES HAVE. *Please Read Each One Carefully And Check The Answer Which Best Reflects How Much That Symptom Has Bothered You During the __Past Three Months__.*

		1 Not at all	2 A little	3 Quite a bit	4 Extremely	
1.	Suddenly scared for no reason	1	2	3	4	K1.
2.	Feeling fearful	1	2	3	4	K2.
3.	Faintness, dizziness, or weakness	1	2	3	4	K3.
4.	Nervousness or shakiness inside	1	2	3	4	K4.
5.	Heart pounding or racing	1	2	3	4	K5.
6.	Trembling	1	2	3	4	K6.
7.	Feeling tense or keyed up	1	2	3	4	K7.
8.	Headaches	1	2	3	4	K8.
9.	Spells of terror or panic	1	2	3	4	K9.
10.	Feeling restless, can't sit still	1	2	3	4	K10.
11.	Feeling low in energy--slowed down	1	2	3	4	K11.
12.	Blaming yourself for things	1	2	3	4	K12.
13.	Crying easily	1	2	3	4	K13.
14.	Loss of sexual interest or pleasure	1	2	3	4	K14.
15.	Poor appetite	1	2	3	4	K15.
16.	Difficulty falling asleep, staying asleep	1	2	3	4	K16.
17.	Feeling hopeless about the future	1	2	3	4	K17.
18.	Feeling blue	1	2	3	4	K18.
19.	Feeling lonely	1	2	3	4	K19.
20.	Feeling trapped or caught	1	2	3	4	K20.
21.	Worrying too much about things	1	2	3	4	K21.
22.	Feeling no interest in things	1	2	3	4	K22.
23.	Thoughts of ending your life	1	2	3	4	K23.
24.	Feeling everything is an effort	1	2	3	4	K24.
25.	Feelings of worthlessness	1	2	3	4	K25.

COPING SECTION

1. Imagine that you are afraid of the dentist and have to get some dental work done. Which of the following would you do? Please answer **yes** or **no** for each choice.

		YES	NO	
a.	I would ask the dentist exactly what s/he was going to do.	1	5	L1_1
b.	I would take a tranquilizer or have a drink before going.	1	5	L1_2
c.	I would try to think about pleasant memories.	1	5	L1_3
d.	I would want the dentist to tell me when I would feel pain.	1	5	L1_4
e.	I would try to sleep.	1	5	L1_5
f.	I would watch all the dentist's movements and listen for the sound of the drill.	1	5	L1_6
g.	I would watch the flow of water from my mouth to see if it contained blood.	1	5	L1_7
h.	I would do mental puzzles in my mind.	1	5	L1_8

2. Imagine that you are being held hostage by a group of armed terrorists in a public building. Which of the following would you do?

		YES	NO	
a.	I would sit by myself and have as many daydreams and fantasies as I could.	1	5	L2_1
b.	I would stay alert and try to keep myself from falling asleep.	1	5	L2_2
c.	I would exchange life stories with the other hostages.	1	5	L2_3
d.	If there was a radio present, I would stay near it and listen to the bulletins about what the police were doing.	1	5	L2_4
e.	I would watch every movement of my captors and keep an eye on their weapons.	1	5	L2_5
f.	I would try to sleep as much as possible.	1	5	L2_6
g.	I would think about how nice it's going to be when I get home.	1	5	L2_7
h.	I would make sure I knew where every possible exit was.	1	5	L2_8

3. Imagine that due to a large drop in sales, it is rumored that several people in your department at work will be laid off. Your supervisor has turned in an evaluation of your work for the past year. The decision about lay-off has been made and will be announced in several days. Please answer **yes** or **no** for each choice.

		YES	NO	
a.	I would talk to my fellow workers to see if they knew anything about what the supervisor's evaluation of me said.	1	5	L3_1
b.	I would review the list of duties for my present job and try to figure out if I had fulfilled them all.	1	5	L3_2
c.	I would go to the movies to take my mind off things.	1	5	L3_3
d.	I would try to remember any arguments or disagreements I might have had with the supervisor that would have lowered his opinion of me.	1	5	L3_4
e.	I would push all thoughts of being laid off out of my mind.	1	5	L3_5
f.	I would tell my spouse that I'd rather not discuss my chances of being laid off.	1	5	L3_6
g.	I would try to think which employees in my department the supervisor might have thought had done the worst job.	1	5	L3_7
h.	I would continue doing my work as if nothing special was happening.	1	5	L3_8

4. Imagine that you are on an airplane, 30 minutes from your destination, when the plane unexpectedly goes into a deep dive and then suddenly levels off. After a short time, the pilot announces that nothing is wrong, although the rest of the ride may be rough. You, however, are not convinced that all is well. Please answer **yes** or **no** for each choice.

		YES	NO	
a.	I would carefully read the information provided about safety features in the plane and make sure I knew where the emergency exits were.	1	5	L4_1
b.	I would make small talk with the passenger beside me.	1	5	L4_2
c.	I would watch the end of the movie, even if I had seen it before.	1	5	L4_3
d.	I would call for the flight attendant and ask her/him exactly what the problem was.	1	5	L4_4
e.	I would order a drink or tranquilizer from the stewardess.	1	5	L4_5
f.	I would listen carefully to the engines for unusual noises and would watch the crew to see if their behavior was out of the ordinary.	1	5	L4_6
g.	I would talk to the passenger beside me about what might be wrong.	1	5	L4_7
h.	I would settle down and read a book or magazine or write a letter.	1	5	L4_8

5. This set of questions deals with ways you've been coping with the stress in your life that goes with your wife/partner possibly having the altered BRCA1 gene associated with risk for breast cancer. Obviously, different people deal with this stress in different ways, but we are interested in how you've tried to deal with it. Each item says something about a particular way of coping. We want to know *to what extent* you've been doing what the item says, how *much* or how *frequently*. Don't answer on the basis of whether it seems to be working, but just whether or not you're doing it. Use these response choices below and try not to let one answer influence another. Make your answers as true FOR YOU as you can.

		I haven't been doing this at all 1	I've been doing this a little bit 2	I've been doing this some 3	I've been doing this a lot 4	
a.	I've been turning to work or other activities to take my mind off things.	1	2	3	4	L7_a.
b.	I've been concentrating my efforts on doing something about her situation.	1	2	3	4	L7_b.
c.	I've been saying to myself "this isn't possible."	1	2	3	4	L7_c.
d.	I've been using alcohol or other drugs to make myself feel better.	1	2	3	4	L7_d.
e.	I've been getting emotional support from others.	1	2	3	4	L7_e.
f.	I've been giving up trying to deal with it.	1	2	3	4	L7_f.
g.	I've been taking action to try to make the situation better.	1	2	3	4	L7_g.
h.	I've been refusing to believe that it is possible she has the gene.	1	2	3	4	L7_h.
i.	I've been saying things to let my unpleasant feelings escape.	1	2	3	4	L7_i.
j.	I've been using alcohol or other drugs to help me get through it.	1	2	3	4	L7_j.
k.	I've been trying to see it in a different light, to make it seem more positive.	1	2	3	4	L7_k.
l.	I've been trying to come up with a strategy for what to do.	1	2	3	4	L7_l.

		I haven't been doing this at all 1	I've been doing this a little bit 2	I've been doing this some 3	I've been doing this a lot 4	
m.	I've been getting comfort and understanding from someone.	1	2	3	4	L7_m.
n.	I've been giving up the attempt to cope.	1	2	3	4	L7_n.
o.	I've been accepting the possibility that she might have the gene.	1	2	3	4	L7_o.
p.	I've been expressing my negative feelings.	1	2	3	4	L7_p.
q.	I've been trying to find comfort in my religion or spiritual beliefs.	1	2	3	4	L7_q.
r.	I've been learning to live with the possibility she might have the gene.	1	2	3	4	L7_r.
s.	I've been thinking hard about what steps to take.	1	2	3	4	L7_s.
t.	I've been praying or meditating.	1	2	3	4	L7_t.
u.	I've been making fun of the situation.	1	2	3	4	L7_u.
v.	I've been giving pep talks and encouraging my wife/partner.	1	2	3	4	L7_v.
w.	I've been denying or hiding my anger around my wife/partner.	1	2	3	4	L7_w.
x.	I've been denying or hiding my own worries around my wife/partner.	1	2	3	4	L7_x.
y.	I've been trying to give my wife/partner opportunities to talk about her worries.	1	2	3	4	L7_y.
z.	I've been trying to find out what my wife/partner is feeling.	1	2	3	4	L7_z.
aa.	I've been avoiding talking about my own problems around my wife/partner.	1	2	3	4	L7_aa.
bb.	I've acted more positive around my wife/partner than I feel.	1	2	3	4	L7_bb.

20

The following questions concern coping with your wife/partner's diagnosis and treatment for cancer:

6. **At your worst**, how distressed did you feel about your wife/partner's diagnosis and treatment of cancer?

                                                                    L8.

    Not at All   Very Much
        1   2   3   4   5   6   7

7. During that time, did you ever have two weeks or more when nearly every day you felt sad, blue, or depressed or in which you lost all interest in things like work or hobbies or things you usually like to do for fun?

                (1) ☐ Yes   (5) ☐ No (Skip to Question 8)   **L9.**

    a. If there was such a two-week period, did your work or relationships suffer?   **L9a.**

                (1) ☐ Yes   (5) ☐ No

    b. If there was such a two-week period, did you get counseling or psychotherapy?   (1) ☐ Yes   (5) ☐ No   **L9b.**

    c. If there was such a two-week period, did you get medication for this problem?   **L9c.**

                (1) ☐ Yes   (5) ☐ No

8. For each of the statements on the following page, indicate the degree to which this change occurred in your life as a result of your wife/partner being diagnosed and treated for breast cancer.
    Please use the following scale:

    1 = I experienced **no** change as a result of my wife/partner's being diagnosed and treated for cancer.

    2 = I experienced this change to a **very small degree** as a result of my wife/partner's being diagnosed and treated for cancer.

    3 = I experienced this change to a **small degree** as a result of my wife/partner's being diagnosed and treated for cancer.

    4 = I experienced this change to a **moderate degree** as a result of my wife/partner's being diagnosed and treated for cancer.

    5 = I experienced this change to a **great degree** as a result of my wife/partner's being diagnosed and treated for cancer.

    6 = I experienced this change to a **very great degree** as a result of my wife/partner's being diagnosed and treated for cancer.

    ☐ Does not apply because I was not with my wife/partner when she was being treated for breast cancer.   **L6.**

		No Change	Very Small Degree	Small Degree	Moderate Degree	Great Degree	Very Great Degree	
a.	My priorities about what is important in life.	1	2	3	4	5	6	L6_a.
b.	I'm more likely to try to change things which need changing.	1	2	3	4	5	6	L6_b.
c.	An appreciation for the value of my own life.	1	2	3	4	5	6	L6_c.
d.	A feeling of self-reliance.	1	2	3	4	5	6	L6_d.
e.	A better understanding of spiritual matters.	1	2	3	4	5	6	L6_e.
f.	Knowing that I can count on people in times of trouble.	1	2	3	4	5	6	L6_f.
g.	A sense of closeness with others.	1	2	3	4	5	6	L6_g.
h.	Knowing I can handle difficulties.	1	2	3	4	5	6	L6_h.
i.	A willingness to express my emotions.	1	2	3	4	5	6	L6_i.
j.	Being able to accept the way things work out.	1	2	3	4	5	6	L6_j.
k.	Appreciating each day.	1	2	3	4	5	6	L6_k.
l.	Having compassion for others.	1	2	3	4	5	6	L6_l.
m.	I'm able to do better things with my life.	1	2	3	4	5	6	L6_m.
n.	New opportunities are available which wouldn't have been otherwise.	1	2	3	4	5	6	L6_n.

9. During the time in which your wife/partner was being treated for breast cancer, how often did you do the following to help her manage the emotional distress?

☐ Does not apply because I was not with my wife/partner when
(-8) she was being treated for breast cancer.

		Never				Very Often	
		1	2	3	4	5	L10a.
1.	Gave her advice?	1	2	3	4	5	L10b.
2.	Went out of your way not to upset her?	1	2	3	4	5	L10c.
3.	Agreed with her to avoid an argument?	1	2	3	4	5	L10d.
4.	Acted more optimistic than you felt?	1	2	3	4	5	L10e.
5.	Kept your own problems to yourself?	1	2	3	4	5	L10f.
6.	Made up after an argument more quickly than before?	1	2	3	4	5	L10g.
7.	Apologized even when you didn't feel you were wrong?	1	2	3	4	5	L10h.
8.	Told her to calm down or relax?	1	2	3	4	5	L10i.
9.	Hid information that may upset her?	1	2	3	4	5	L10j.
10.	Stayed out of her problems?	1	2	3	4	5	L10k.
11.	Let your own problems take a "back seat" to her needs?	1	2	3	4	5	L10l.
12.	Gave her space when she was upset?	1	2	3	4	5	

*We thank you for all of your valued
participation in this study.*

☐☐☐☐ – ☐

WOMEN'S HEALTH STUDY
Partner Post-Results Questionnaire

Today's Date _____   ID# _____

Spouse/Partner Post-Results Questionnaire
(8 Month Follow-Up after Partner Received Results)

Genetic Testing

1. Did you go with your spouse/partner to get her test results?
    P6

    (1) ☐ Yes   (5) ☐ No   (-8) ☐ Not Applicable (she received results by mail
    or over the telephone)

2. To your understanding, what were the results of your spouse/partner's genetic testing?   P5

    0 ☐   An altered gene was <u>NOT FOUND</u> for either BRCA1 or BRCA2

    └─► Even though no alteration was found for BRCA1 or BRCA2, Do you believe
        there is a possibility that your spouse/partner has another altered gene
        conveying an increased risk for breast and ovarian cancer?

        (1) ☐ Yes   (5) ☐ No   N13

    1 ☐   An altered gene was <u>FOUND</u> for either BRCA1 or BRCA2

    3 ☐   <u>I don't know</u> the results

3. When your spouse/partner received her genetic test results, what were your reactions?
    ☐ Not Applicable -- I don't know my partner's results.

		Strongly Disagree				Strongly Agree	
a.	I felt wonderful.	1	2	3	4	5	B18c_a.
b.	I felt depressed.	1	2	3	4	5	B18c_b.
c.	I felt she had been told what she knew all along.	1	2	3	4	5	B18c_c.
d.	I felt relieved about being more certain.	1	2	3	4	5	B18c_d.
e.	I did not believe the results.	1	2	3	4	5	B18c_e.
f.	I fell apart emotionally.	1	2	3	4	5	B18c_f.
g.	I felt anxious.	1	2	3	4	5	B18c_g.
h.	I felt angry.	1	2	3	4	5	B18c_h.

		Strongly Disagree				Strongly Agree	
i.	I felt prepared for the future.	1	2	3	4	5	B18c_i.
j.	I felt worried about the future.	1	2	3	4	5	B18c_j.
k.	I felt she had done all she needed to do.	1	2	3	4	5	B18c_k.
l.	I did not feel very differently.	1	2	3	4	5	B18c_l.
m.	[For those who have daughters]. I wanted my daughters to be tested as soon as possible.	1	2	3	4	5	B18c_m.

4. To what extent did you do the following <u>after</u> your spouse/partner got her genetic results?

		Never				Very Often	
a.	Gave her advice?	1	2	3	4	5	L10a
b.	Went out of your way not to upset her?	1	2	3	4	5	L10b
c.	Agreed with her to avoid an argument?	1	2	3	4	5	L10c
d.	Acted more optimistic than you felt?	1	2	3	4	5	L10d
e.	Kept your own problems to yourself?	1	2	3	4	5	L10e
f.	Made up after an argument more quickly than before?	1	2	3	4	5	L10f
g.	Apologized even when you didn't feel you were wrong?	1	2	3	4	5	L10g
h.	Told her to calm down or relax?	1	2	3	4	5	L10h
i.	Hid information that may upset her?	1	2	3	4	5	L10i
j.	Stayed out of her problems?	1	2	3	4	5	L10j
k.	Let your own problems take a "back seat" to her needs?	1	2	3	4	5	L10k
l.	Gave her space when she was upset?	1	2	3	4	5	L10l

5. How distressed were <u>you</u> when you heard your spouse/partner's genetic test results?

Not At All Distressed				Very Distressed	Doesn't Apply *I don't know what her results are*
1	2	3	4	5	-8

6. In your opinion, how distressed was <u>your spouse/partner</u> when she received genetic test results?

Not At All Distressed				Very Distressed
1	2	3	4	5

7. Overall, do you regret your spouse/partner's decision to obtain her results?

Not At All				Very Much So
1	2	3	4	5

8. Do you think it is beneficial to have genetic testing for risk of breast and ovarian cancer available to women?

B55

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

For the next set of questions, we would like to ask about the impact your spouse/partner's receiving results has had on different areas of your family's life.

9. On the whole, what effect has her testing had on <u>your life</u>?

Very Negative Effect	Somewhat Negative Effect	No Effect	Somewhat Positive Effect	Very Positive Effect
1	2	3	4	5

N15

10. Think about your everyday <u>family life</u>. What effect would you say getting the genetic test results has had?

Very Negative Effect	Somewhat Negative Effect	No Effect	Somewhat Positive Effect	Very Positive Effect
1	2	3	4	5

N16

11. What effect has your spouse/partner getting her results had on your <u>work</u> in and outside of the home?

Very Negative Effect	Somewhat Negative Effect	No Effect	Somewhat Positive Effect	Very Positive Effect
1	2	3	4	5

N17

12. How has it affected your anxiety about the <u>future</u>?

Less Anxiety	No Change	More Anxiety
1	2	3

N18

13. What effect has your spouse/partner getting her results had on your concerns for your <u>child's/children's future</u>?

Very Negative Effect	Somewhat Negative Effect	No Effect	Somewhat Positive Effect	Very Positive Effect	Not Applicable
1	2	3	4	5	-8

N19

14. Psychologists have developed a standardized scale for comparing stressful situations with 0 representing no stress and 100 representing the greatest stress. Using this scale, North American samples have given the following ratings to some stressful events:

Change in residence is assigned a stress score of 20

Pregnancy is 40

Death of a close family member is 63

Death of a spouse is 100

Keeping in mind the ratings listed above, Please use any number between 0-100 with 0 representing no stress and 100 representing the greatest stress:

a. <u>For only those whose partners have had breast or ovarian cancer</u>, how would you rate <u>your</u> stress level when you heard your partner had been diagnosed?

Spouse/partner's diagnosis of Cancer _____

b. Now, how would you rate <u>your</u> stress when you heard the results of your spouse/partner's genetic testing?

Stress of hearing partner's genetic results _____

N4

15. How often have you discussed genetic testing for breast and ovarian cancer with your spouse/partner?

B51

Never	Rarely	Sometimes	Often
1	2	3	4

15a. When you have these discussions, who generally initiates them?   B52

You	Your partner	Equally	Not Applicable
1	2	3	-8

15b. How satisfied are you with these discussions?   B53

Not At All	A Little	Somewhat	A Great Deal	Not Applicable
1	2	3	4	-8

16. How often does your spouse/partner express concern and seek support from you about the risk of breast and ovarian cancer to herself and women in her family?

Never	Rarely	Sometimes	Often
1	2	3	4

16a. How much of a burden is this on you?   B50

Not At All	A Little	Somewhat	A Great Deal	Not Applicable
1	2	3	4	-8

17. Overall, how much do you want your opinion to be taken into account in your partner's decisions **about what to do about her risk** for breast and ovarian cancer?   B58

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

18. Overall, what do you believe your spouse/partner's risk to be of developing breast or ovarian cancer (or developing breast or ovarian cancer again) **in the near future**?   B9b

0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
0	1	2	3	4	5	6	7	8	9	10

19. Overall, what do you believe her risk to be of developing breast or ovarian cancer (or developing breast or ovarian cancer again) **at some point in her lifetime?**   B10b

0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
0	1	2	3	4	5	6	7	8	9	10

20. At the present time, do you feel you are adequately informed concerning your spouse/partner's risk for cancer and what can be done about it?

Not At All						Very Much
1	2	3	4	5	6	7

21. At the present time, do you feel you are adequately informed about the benefits and drawbacks of options available to women who have an altered BRCA1/BRCA2 gene?   B46

Not At All						Very Much
1	2	3	4	5	6	7

22. How often do you worry about your partner/spouse developing breast/ovarian cancer (again)?

Not At All				All the Time
1	2	3	4	5

B27aa

23. To what extent do these worries interfere with your every day life?

Not At All				All the Time
1	2	3	4	5

B28a

24. How often do you worry about developing cancer yourself?

Not At All				All the Time
1	2	3	4	5

B31

Symptoms of Strain

LISTED BELOW ARE SOME SYMPTOMS OF STRAIN THAT PEOPLE SOMETIMES HAVE. *Please Read Each One Carefully And Circle The Answer Which Best Reflects How Much That Symptom Has Bothered You During the* **Past Three Months**.

		Not at all	*A little*	*Quite a bit*	*Extremely*	
1.	Suddenly scared for no reason	1	2	3	4	K1
2.	Feeling fearful	1	2	3	4	K2
3.	Faintness, dizziness, or weakness	1	2	3	4	K3
4.	Nervousness or shakiness inside	1	2	3	4	K4
5.	Heart pounding or racing	1	2	3	4	K5
6.	Trembling	1	2	3	4	K6
7.	Feeling tense or keyed up	1	2	3	4	K7
8.	Headaches	1	2	3	4	K8
9.	Spells of terror or panic	1	2	3	4	K9
10.	Feeling restless, can't sit still	1	2	3	4	K10
11.	Feeling low in energy--slowed down	1	2	3	4	K11
12.	Blaming yourself for things	1	2	3	4	K12
13.	Crying easily	1	2	3	4	K13
14.	Loss of sexual interest or pleasure	1	2	3	4	K14
15.	Poor appetite	1	2	3	4	K15
16.	Difficulty falling asleep, staying asleep	1	2	3	4	K16
17.	Feeling hopeless about the future	1	2	3	4	K17
19.	Feeling blue	1	2	3	4	K19
19.	Feeling lonely	1	2	3	4	K19
20.	Feeling trapped or caught	1	2	3	4	K20
21.	Worrying too much about things	1	2	3	4	K21
22.	Feeling no interest in things	1	2	3	4	K22
23.	Thoughts of ending your life	1	2	3	4	K23
24.	Feeling everything is an effort	1	2	3	4	K24
25.	Feelings of worthlessness	1	2	3	4	K25

26.   To what extent are any of the above current symptoms a result of your partner getting genetic testing?

Not At All	A Little	Some	Quite a Bit	Very Much	
1	2	3	4	5	K26

Your Views of Prevention and Treatment

1. To what extent do you agree or disagree with the following statements?

		Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Somewhat Agree	
a.	In the next year, there will be dramatic breakthroughs in the <u>prevention</u> of breast and/or ovarian cancer.	1	2	3	4	5	N7a
b.	In the next year, there will be dramatic breakthroughs in the <u>treatment</u> of breast and/or ovarian cancer.	1	2	3	4	5	N7b
c.	In the next year, the length of <u>survival</u> after diagnosis of breast cancer will increase.	1	2	3	4	5	N7c
d.	In the next year, the length of <u>survival</u> after diagnosis of ovarian cancer will increase.	1	2	3	4	5	N7d
e.	In the next 5 years, there will be dramatic breakthroughs in the <u>prevention</u> of breast and/or ovarian cancer.	1	2	3	4	5	N7e
f.	In the next 5 years, there will be dramatic breakthroughs in the <u>treatment</u> of breast and/or ovarian cancer.	1	2	3	4	5	N7f
g.	In the next five years, the length of <u>survival</u> after diagnosis of breast cancer will increase.	1	2	3	4	5	N7g
h.	In the next five years, the length of <u>survival</u> after diagnosis of ovarian cancer will increase.	1	2	3	4	5	N7h
i.	In the future, all women will routinely receive genetic testing for risk of breast and ovarian cancer.	1	2	3	4	5	N7i

We thank you for all of your valued participation in this study.

B.VIII. Telephone Contact Sheet

Participant Name: _____

TELEPHONE CONTACT ATTEMPTS

Date	Time	Outcome	Comments

Hello. May I please speak to [participant's name]?

My name is [caller's name]. I am calling from the Genetic Testing Study at the University of Pennsylvania. Recently we mailed you a letter notifying you that your genetic testing results are available, along with a questionnaire to complete as part of our ongoing study. We haven't heard back from you, and just wanted to check in to see that you received the letter, and to answer any questions you may have about the study.

☞ IF NEEDS ANOTHER LETTER &/OR QUESTIONNAIRE:

Would it be alright with you if we sent another letter and questionnaire?

    IF YES: [confirm address]: _____

Where are you in your decision about whether or not to get the results of your genetic testing?

❑   1. DECIDED NOT TO GET RESULTS
❑   2. DECIDED TO GET RESULTS, BUT SOMETIME IN THE FUTURE
❑   3. DECIDED TO GET RESULTS, AWAITING COUNSELING NOW
❑   4. UNDECIDED; STILL THINKING ABOUT IT
❑   5. ALREADY GOT RESULTS
❑   6. NOT PLANNING TO PARTICIPATE ANY LONGER

1. DECIDED NOT TO GET RESULTS

Would you mind sharing your reasons why you decided not to get your test results?

We appreciate your participation in this study, and respect your decision not to get your results. We would like to hear from women who choose not to get results, as well as from those who do. May we send you a questionnaire to complete for us?

2. DECIDED TO GET RESULTS, BUT SOMETIME IN THE FUTURE:

Would you mind sharing the reasons you decided to wait to get results?

When you do decide that you're ready to get your results, you can contact us. Do you still have the contact information? (Kathy Calzone: 215-349-8141; or Melissa Racioppo: 215-662-4738) In the meantime, may we send you a questionnaire to complete for our ongoing study, while you decide about when to get results?

3. DECIDED TO GET RESULTS, AWAITING COUNSELING NOW:

Have you already received your genetic counseling? Do you have any questions about what happens next in the process?

4. UNDECIDED; STILL THINKING ABOUT IT:

Would you mind sharing your thoughts about testing? What are the factors that are most important in deciding whether or not to get results?

Do you feel that the genetic testing results would change the way you approach your health care?

Are there other things going on in your life right now that make it difficult to make a decision about getting test results?

Please remember that you can contact us at the University if you do decide to get your test results sometime in the future. In the meantime, may we send you a questionnaire to complete for our ongoing study, regardless of what you decide about getting results?

5. ALREADY GOT RESULTS:

When did you get your results? And from whom did you receive them? Thank you, and thank you for contributing your time and energy to this study.

Date received results:	
Who delivered results:	

We're interested in knowing how the process of testing and results-disclosure has gone for people. May we send you a questionnaire to complete for us that asks about your experiences with testing?

Confirm address:

 [CHECK ANDREA MAILING LIST; IF GOT RESULTS BUT NO RESPONSE TO QUESTIONNAIRE, THEN SEND NEW RETROSPECTIVE QUESTIONNAIRE]

6. IF NOT PLANNING TO PARTICIPATE ANY LONGER:

May I ask why you would prefer not to participate any longer in the study?

IF FRUSTRATED WITH THE PROCESS: The process has taken longer than any of us anticipated. As new mutations have been discovered, we've decided to re-run some of the testing to be sure the results we give are accurate and up-to-date. Also, the testing technology has been developing along with the discoveries in the genes themselves, and this has delayed results as well. We certainly appreciate your patience during this process, and understand the wait has been frustrating.

Do you have any other questions about the study, or receiving your test results?
Thank you very much for your time, and for your help with this project. If you have questions in the future, please feel free to call Kathy Calzone at (215) 349-8141, or Melissa Racioppo at (215) 662-4738.

APPENDIX C: PUBLICATIONS

What Do Ratings of Cancer-Specific Stressors Mean Among High Risk Women

Anticipating Testing for BRCA1/BRCA2?

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What Do Ratings of Cancer-Specific Stressors Mean Among High Risk Women

Anticipating Testing for BRCA1/BRCA2?

Abstract

Women recruited from a hereditary cancer registry provided ratings of distress associated with different aspects of high-risk status and genetic testing, and completed measures of general psychological distress, emotional and social health, and role functioning. Overall, high-risk status was rated as more distressing than undergoing genetic testing. Women without a personal history of cancer rated the level of distress associated with a positive test result to be greater than that associated with high-risk status. In contrast, level of distress associated with a positive test result was not significantly different from that associated with high-risk status for women with a personal history of cancer. Furthermore, women with a personal cancer history also anticipated that if they had an altered gene associated with increased risk of cancer it would be less distressing than their diagnosis of cancer had been. Women with the highest ratings of cancer-related stress were less inclined to obtain testing, but were not more generally distressed or maladjusted. The need to interpret psychological distress and the stressfulness of genetic testing among high-risk women with respect to relevant comparison data is discussed.

Key Words: Genetic Testing, Psychological Distress, Methodology

INTRODUCTION

The cloning of BRCA1 [Miki et al., 1994; Tavtigian et al., 1996] and BRCA2, [Wooster et al., 1995] and the resultant availability of genetic testing, offers women with a familial history of breast and ovarian cancer the prospect of obtaining more accurate estimates of their personal risk of cancer. Yet, enthusiasm for the potential benefits of genetic testing has been tempered by concerns about the possible adverse consequences of testing. For example, it has been widely assumed that women with a familial risk of cancer are a psychologically vulnerable population, and that disclosure of the results of genetic testing could prove traumatic.

At the time of the initial identification of the BRCA1/2 gene mutations, health care providers and researchers had only limited experience in offering individuals testing for risk of cancer. Hence, it was quite plausible that a woman's learning that she carried an altered gene associated with a high risk of developing cancer [Biesecker et al., 1993; Dudokede-Wit et al., 1997; Lerman, Daly, Many, and Balshem, 1994; Lynch et al., 1997], or even confronting the dilemma of whether to seek such information [Lerman et al., 1998], could constitute potent psychological stressors. Consistent with these concerns, women with familial histories of breast and ovarian cancer anticipated becoming depressed and anxious, and that they would suffer decreased quality of life if found to be carriers of an altered gene [Lerman et al., 1994].

Yet, a more recent study of a large sample of women with familial histories of cancer who were anticipating genetic testing, revealed that these women were not psychologically distressed [Coyne, et al., 2000]. The prevalence of clinically significant distress was in the range that would be expected for a sample of community-residing women (21%), and substantially lower than what is typically found in primary medical care samples (30-35%; Fechner-Bates, Coyne, & Schwenk, 1994). Assessments with standardized psychiatric interviews further

revealed that rates of clinical depression and anxiety disorder were so low as to render routine

screening inefficient. A similarly low rate of distress was found among women recruited to a

clinical trial comparing alternate means of pretest education for BRCA1 testing [Audrain et al.,

1997]. Furthermore, accumulating studies have indicated that even notification of positive

mutation status is not typically associated with significant psychological distress [Croyle et al.,

1997; Lerman et al., 1996].

Questions of whether high-risk women anticipating testing are a distressed or clinically

depressed group, and whether disclosure of positive mutation status has a deleterious effect on

psychological adjustment, can be addressed with assessments using standardized measures of

distress and validated diagnostic interview schedules. Such measures allow us to contrast the

adjustment of these women with relevant comparison-control groups and with normative data.

However, there has also been interest in cancer-specific worries and other measures of distress

directly related to high-risk status and genetic testing. Because these measures are specific to

these potential sources of stress, they may also be more sensitive indicators of women's

experience, and better predictors of behavior [Croyle, et al., 1997; Lerman, et al., 1996; Lerman,

et al., 1997].

Investigators often wish to attach substantive meaning to particular scores on such

measures. Yet, even when a measure has been correlated with standardized measures of distress

or reports of health behaviors, the significance of a particular score remains ambiguous. For

instance, using common cancer-specific items, McCaul et al. [1998] reported average breast

cancer worry among women with a family history of cancer as 2.65 ($\underline{SD}$ = .69) on a 1-5 scale.

Further, these women rated that worries interfered with their daily activities, on average, at 1.17

($\underline{SD}$ = .38) on a 1 - 5 scale. Based on these results, the investigators concluded that some women

with a family history may experience chronic worry about breast cancer [McCaul et al., 1998].

Similarly, Lerman, Kash, and Stefanek [1994] assessed cancer worry and interference among

younger women with a family history of cancer. Average worry was reported as 2.53 (SD =

1.66) on a 1-7 scale, and the impact of these worries on daily functioning as 1.54 (SD = .84) on a

scale of 1-4. These investigators concluded, "Many of these women may have breast cancer

worries that have the potential to compromise their daily functioning" [Lerman, et al., 1994; p.

175].

At least two strategies exist for validating the interpretation of particular scores on a

cancer-specific measure. The first is to compare women's ratings of multiple sources of cancer-

related stress. With respect to genetic testing, it is important to note that testing is most

appropriate for women who are already considered at high risk based on family history or ethnic

background. This implies that women facing decisions about testing may already have cancer-

specific distress because of their awareness of their risk of cancer. Obtaining genetic testing may

even be viewed as a means of their coping with this pre-existing stress, rather than simply the

imposition of a new stressor. The stress associated with testing, and the threat of obtaining

positive findings, need to be evaluated in this context. A second validation strategy is to use

standardized measures of general distress and social and emotional role functioning to anchor

ratings of cancer-specific distress and the interference of such concerns with everyday life.

This paper provides such comparisons in sample of women participating in a hereditary

breast and ovarian cancer registry. Items assessing cancer- and testing-specific distress were

examined among women with a familial history of cancer. Women indicated their actual or

anticipated distress in response to a number of cancer- or risk-related stressors (i.e., being a

member of a family with a cancer history, being offered genetic testing, and the possibility of

being told that they were positive or negative for a genetic mutation). Ratings of these sources of

stress were compared and then evaluated with respect to a widely used, standardized self-report

measure of psychological distress, the 25-item version of the Hopkins Symptom Checklist

(HSCL-25)[Derogatis, et al., 1974], and measures of functioning from the SF-36 [Ware &

Sherbourne, 1992]. The goals were to provide a comparative evaluation of the cancer-related

stress experienced by these high-risk women, and to anchor particular scores on measures of

cancer-related distress to validated, more general measures of distress and functioning. Finally,

we examined these variables with respect to the women's intention to obtain results of genetic

testing.

MATERIALS AND METHODS

Sample and Recruitment Procedure

Women participating in the study were 196 women selected from the registry of the

Hereditary Breast and Ovarian Cancer Study conducted by the University of Pennsylvania Cancer

Center and the University of Michigan. Procedures used in the recruitment of women to this

registry are described elsewhere [Coyne, et al., 2000; Coyne & Anderson, 1999]. A

heterogeneous set of eligibility criteria had been applied in the original recruitment of these

women to the registry. Specifically, women having a previous diagnosis of breast or ovarian

cancer were eligible if they had at least one other first- or second-degree family member with one

of these forms of cancer. Women without a personal history of breast or ovarian cancer were

required to have two relatives with breast or ovarian cancer. Finally, women from families with

both breast and ovarian cancer were oversampled.

A regular newsletter sent to participants of the registry informed them of this study aimed at

examining the psychological factors associated with anticipating and receiving genetic testing.

The newsletter also provided the opportunity to decline further solicitation concerning this study.

Questionnaires and consent forms were then mailed to the homes of those who did not decline,

along with a cover letter explaining that on receipt of their questionnaires a researcher would

contact them to schedule a telephone interview. Only 54 (9%) of the 633 eligible women who

were mailed questionnaires declined participation. An additional 102 (16%) were unable to be

contacted because either their available addresses and/or telephone numbers were no longer valid

or no questionnaire was returned despite efforts to reach them by a follow-up letter and telephone

calls. The majority of this latter group did not represent passive refusals, but rather had simply

been lost to the registry. Data reported in this article were derived from the questionnaire portion

of the baseline assessment. Questionnaire items assessing cancer-related distress were not

included in the original version of the questionnaire packet, and only the 196 participants who

completed the latter version of the questionnaire were included in the analyses for the present

paper. The final sample consisted of 83 with a personal history of breast or ovarian cancer, and

113 who did not have such a history.

Measures

Distress Associated with Various Threats.   A series of questions was used to assess

distress associated with threats related to: (a) being a member of a high-risk family; (b) being

offered genetic testing; and (c) the possibility of testing negative or (d) positive for a gene

mutation. Responses were recorded on a 5-point Likert-type scale (1 = no distress, 5 = very

much distress). Additionally, level of distress related to receiving a breast cancer diagnosis was

examined among women with a history of the disease.

General Psychological Distress. The 25-item version of the Hopkins Symptom

Checklist (HSCL-25) was used as a measure of psychological distress. The scale consists of

items from anxiety and depression clusters of the HSCL-90, as well as items assessing somatic

symptoms (poor appetite; difficulty falling asleep or staying asleep). Identical items with

inconsequential differences in wording are found on the Symptom Checklist 90 (SCL-

90)[Derogatis & Cleary, 1977]. The HSCL-25 has been found to be highly correlated with the

standard 58-item version Hopkins Symptom Checklist [Hesbacher, Rickels, Downing, &

Stepansky, 1978], and has been widely used to screen medical patients for psychiatric difficulties

[Fink et al., 1995]. Furthermore, Hough and colleagues [1982] found that, with a cutoff of 44 for

caseness, the HSCL-25 was comparable or superior to the CES-D [Radloff, 1977] in detecting

psychiatric disorder. In addition, this scale has been used extensively with healthy, physically ill,

and psychiatric samples where adequate rates of reliability have been reported [Cohen, Coyne, &

Duvall, 1993; Coyne, Kessler, Tal, & Turnbull, 1987; Coyne & Smith, 1991; Cranford, Coyne,

Sonnega, & Nicklas, 1998; Hesbacher, Rickels, Morris, Newman, & Rosenfeld, 1980].

Consistent with past studies, coefficient alpha for the HSCL-25 was found to be .92.

Social and Emotional Health. The RAND Medical Outcomes Study Short-Form-36

Health Survey (SF-36; Ware & Sherbourne, 1992) was used to assess levels of emotional and

social functioning and role limitations due to emotional problems. This 36-item measure has

been used extensively to measure physical, social, and emotional health among various healthy

and medical populations (e.g., Gilboe, Kvien, & Husby, 1999; Woolf, Rothemich, Johnson, &

Marsland, 1998; Ganz et al., 1995; Chie, Huang, Chen, & Chang, 1999). The psychometric

properties of the measure are well established [Kantz et al.,1992; McHorney, Ware, & Raczek,

1993; Brazier , Jones, & Kind, 1993; Jenkinson, Coulter, & Wright, 1993] and it has been used

to demonstrate the validity of several quality of life instruments (e.g., Litwin et al., 1998; Stier et

al., 1999; Eiser, Kopel, Cool, & Grimer, 1999).

Intention to Obtain Genetic Testing. Intention to obtain genetic testing was assessed with a single item. The seven response options ranged from "Definitely Not" to "Definitely, Immediately." Scores were highly skewed, with most (56.3%) indicating an interest in receiving test results, and over two-thirds (68%) endorsing the two response options indicating an interest in receiving results immediately. Therefore, scores were dichotomized with these two response options versus the rest.

RESULTS

The analyses were conducted in four stages. First, descriptive statistics were generated for the demographic and clinical characteristics of the study sample. Next, women with and without a history of cancer were compared with respect to levels of distress. We then explored the association between cancer-specific distress and standardized measures of general distress. Finally, the association between measures of distress and intention to obtain genetic testing was examined.

Characteristics of the Study Population. The sample was predominantly Caucasian (98%), had at least some college education (82.5%), were married (80.0%), had children living at home (65.6%), and worked for pay outside of the home (63%). Fifty-five percent of women reported a household income of at least $60,000 per year. These characteristics are consistent with findings for the larger sample from which these women were drawn [Coyne et al., 2000] and those of other studies indicating that women who seek genetic testing are generally well-educated and of high social economic status [Codori, Hanson, & Brandt, 1994; Kash et al., 1997]. The age of participants was also consistent with previous research ($\underline{M}$ = 46.7 years, Range = 21-78 years). However, women without a prior cancer diagnosis were younger ($\underline{M}$ = 44.53, SD = 11.85) than

women who had been previously diagnosed with cancer (M = 49.57, SD = 12.26) (t [186] = 2.94, p < .001). Age was, therefore, introduced as a covariate in analyses comparing these groups.

Table I presents means and standard deviations for the key measures of cancer- specific distress, general psychological distress and adjustment.

Insert Table I About Here

Levels of Cancer-Specific and General Psychological Distress and Emotional and Social Adjustment. Overall, 50.6% of women report "much" or "very much" distress related to being a member of a high-risk family, and 56.1% report this degree of distress related to the possibility of testing positive for a BRCA1/BRCA2 mutation. In contrast, 74.7% of participants report "little" or "no" distress related to being offered genetic testing, and 88.9% report this degree of distress related to the possibility of testing negative for BRCA1/BRCA2 mutation.

A 4 (Source of Threat) x 2 (Personal History of Cancer) split-plot ANCOVA was performed on the cancer-specific distress scores while controlling participant age. A main effect was detected, indicating differences in distress for sources of threat (F[3,169] = 209.16). Specifically, being a member of a high risk family was found to be more distressing than either receiving genetic testing (F[1,173] = 278.39, p<.001) or being found to not carry a mutation (F[1,172] = 417.34, p<.001). Similarly, more distress was attributed to receipt of a positive test result than to being tested (F[1,173] = 291.04, p<.001) or receiving a negative test result (F[1,172] = 382.52, p<.001). Receiving a negative test result was less distressing than simply getting tested (F[1.172] = 17.20, p < .001). Distress related to being a member of a high risk family did not differ from that of testing positive for a genetic mutation (F[1,173] = 0.04, ns).

The main effect for history of breast or ovarian cancer was not significant (F[1,170] = 0.07, ns).

A significant interaction was found for cancer history x source of threat (F[3,169] = 2.71, p<.05). Among women without a history of cancer, being from a high risk family was less distressing than testing positive for the altered gene (F[1,101] = 5.45, p<.05), but more distressing than being offered testing (F[1,101] = 182.19, p<001). Among women with a history of cancer, being in a high-risk family was more distressing than being offered testing (F[1,71] = 107.20, p<.001). However, the level of distress reported for being in a high risk family and testing positive were not significantly different (F[1,71] = 2.58, ns).

Only women with a history of cancer were asked the question concerning how distressing it was to be diagnosed with cancer. Higher levels of distress (i.e., "much" and "very much") were reported by 87% of these women. When distress ratings were reanalyzed with this item included, it was found that a diagnosis of cancer was more distressing than what was anticipated for testing positive (F[1,70] = 39.61, p<.001).

Consistent with data reported from the larger registry from which this sample was drawn [Coyne et al., 2000], there were no differences in general psychological distress as a function of cancer history (F[1,185] = 0.48, ns). Similarly, emotional functioning, social functioning, and role limitations did not differ as a function of cancer history (emotional functioning: F[1,181] = 0.83, ns; social functioning: F[1,185] = 1.22, ns; role limitations: F[1,179] = 0.01, ns). Comparison of means to scale norms suggests that this sample is healthy and well- functioning. The women were above population norms for all scales of the SF-36 examined.

When correlations among the ratings of cancer-specific distress were examined for the full sample, distress from obtaining testing and distress anticipated from testing positive were found to be related (r=32, p<.001). This was replicated in the sample of women who had a history of

cancer (r=.23, p<.05), and was the only significant correlation found. However, among women

without a history of cancer, all of these variables, except testing negative, correlated (rs=.23 to

.43, all p<.05). These findings suggest that the degree of distress associated with various aspects

of being at risk reflected more general concerns with high-risk status.

Anchoring Of Ratings of Cancer-Specific Distress

To understand the meaning of distress related to genetic testing and risk status with

respect to more general functioning, scores on these variables were anchored to standardized

measures of general distress and social/ emotional heath (i.e., the HSCL-25, and the SF-36).

Within each source of threat, a series of 2 (cancer history) x 5 (level of distress for a given threat)

ANCOVAs were conducted with HSCL-25 and SF-36 as the dependent variables. Results were

remarkably consistent across the multiple tests, indicating that distress ratings for particular

threats were not associated with general distress or maladjustment. Even those women endorsing

the highest level of distress from specific threats fell below the cutpoint for clinically significant

distress on the HSCL-25, and above the norm for social and emotional health and role

functioning on the SF-36. The one exception was in the general distress analysis of threat related

to testing negative for a BRCA1/BRCA2 mutation (F [4,96] = 2.88, p < .05). Post-hoc analyses

revealed that women without a cancer history who reported very low levels of distress (i.e.,

endorsed a score of 2) and scored significantly higher on the HSCL-25 (M= 44.62) than similar

women reporting no distress from testing negative for a mutation (M = 36.64; F[1,86] = 10.30, p

< .01).

Intention to Obtain Genetic Testing.

As noted above, there was high interest in obtaining the results of genetic testing in this

sample. Interest was not related to general psychological distress (t [57] = 0.78, ns) or distress

associated with being in a high-risk family (t [178] = -0.03, ns). However, women not intending

to obtain testing were characterized by anticipating more distress if offered testing (t [174] =

5.75, p < .001), and if they were to test positive for the altered gene (t [174] = 3.51, p = .001).

DISCUSSION

The offering of genetic testing for risk of breast and ovarian cancer needs to be informed

by a thorough understanding of the psychological vulnerability of the individuals seeking testing

and the risks posed by testing. However, many individuals seeking genetic testing are already

aware of their heightened risk for disease, and their reactions to genetic testing need to be

evaluated in this context. The present findings add to the weight of evidence that genetic testing

for BRCA1/BRCA2 mutations may not be as distressing as widely presumed. This study has

clarified the clinical significance of cancer-specific distress by anchoring ratings with validated

measures of general distress and functioning.

Women anticipating testing reported already being distressed by their heightened risk of

cancer based on family history, and they viewed the prospect of testing as less stressful than

being aware of this familial risk. While high-risk women without a personal history of cancer

anticipated they would be distressed if they were informed they had an altered BRCA1/BRCA2

gene, higher distress was not associated with heightened general psychological distress or

maladjustment. Women who have previously been diagnosed with breast or ovarian cancer

anticipated that, if they were informed they had an altered BRCA1/BRCA2 gene, it would be

less distressing than their diagnosis of cancer had been. There was some evidence that women

who anticipated the most distress if they were found to have an altered gene would opt out of

receiving their results, although overall interest expressed in obtaining results was high.

Ratings of the distress associated with high-risk status or with the finding of an altered gene were not related to women's levels of general psychological distress or emotional and social functioning. Even women attributing the most distress to high-risk status, or anticipating the worst reaction to a finding that they had an altered gene, were relatively well-adjusted.

These findings suggest that the distress associated with genetic testing should be evaluated as part of a larger stress process associated with high-risk status. Obtaining genetic testing may less stressful than merely living with the awareness of a familial risk for cancer. For women with family histories of cancer, genetic testing may be construed as a tool for coping with, and perhaps resolving, the stress of high-risk status, even if it carries the threat of a positive finding. Clearly, interest in testing is not dampened by distress related to testing except for those women who would be most distressed by learning that they had an altered gene. Regardless, the psychological risks and benefits of testing should be evaluated in the larger context of the lives of individuals seeking testing.

A broader implication of our findings is that in order to develop an increased understanding of the adjustment of individuals seeking or receiving genetic testing results, data concerning the psychological aspects of genetic testing needs to be anchored to standardized measures and compared to other relevant stressors and comparison groups. It is not sufficient to cite a particular mean distress score or percent of individuals scoring above a clinical cut-point as evidence that all of this distress can be attributed to genetic testing. For example, there are consistent findings that a third of all patients found in primary care waiting rooms are distressed [Fechner-Bates, Coyne, & Schwenk, 1994]. In comparison, the rates of distress found among women seeking genetic testing for BCA1/2 are lower [Audrain et al., 1997; Coyne et al., 2000]. This raises the issue of whether there is any attributable risk of enduring distress associated with

high-risk status, seeking testing, or even disclosure of being a carrier of an altered gene. This may particularly salient when the self-selection process of seeking and receiving genetic testing is taken into account.

It may be that the mental health issues associated with genetic testing for risk of breast and ovarian cancer have been overemphasized. Mental health screening and following up on positive screens can be costly, particularly given that the low specificity of screening instruments is such that most positive screens do not indicate a need for services [Coyne et al., 2000]. Resources that might otherwise be consumed in extensive psychological screening may be better deployed in increasing the routine support and information available to individuals contemplating testing, and in ensuring that decisions to obtain testing are informed, are not coerced, and that the best use is made of the resulting information. Specialized mental health services should be available for those who wish to utilize them, but we should be prepared for the uptake being low.

As testing becomes more available, researchers and clinicians should be careful about casually dismissing the psychological issues associated with genetic testing, particularly as testing moves from highly select research populations to less self-selected community samples. Yet, in continuing to monitor psychological aspects of genetic testing, we should remain cognizant of the need to make relevant comparisons to representative samples of persons drawn from other situations, and to anchor ratings of stress and distress in some meaningful fashion. Appropriate interpretations of findings that some percentage of individuals involved in genetic testing are distressed, that they anticipate genetic testing to be stressful, or that they have particular levels of breast cancer worry, can only be made with reference to such data.

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TABLE I. Means and Standard Deviations of Distress and Functioning Variables.

Distress Variables	(+) Breast Cancer History	(-) Breast Cancer History	Total Sample
Being a member of a high risk family	3.77 (1.2)	3.47 (1.0)	3.60 (1.1)
Testing positive for the gene mutation	3.49 (1.4)	3.74 (1.2)	3.63 (1.3)
Testing negative for the gene mutation	1.35 (0.8)	1.45 (0.9)	1.40 (0.9)
Being offered testing	1.82 (1.1)	1.85 (1.1)	1.84 (1.1)
Distress associated with diagnosis of cancer	4.51 (0.8)	-----	---
HSCL-25	37.31 (9.9)	38.37 (9.4)	37.94 (9.6)
SF-36 Mental health	73.8 (16.5)	74.25 (15.9)	74.07 (16.1)
SF-36 Role limitations due to emotional problems	77.62 (35.8)	77.98 (34.8)	77.84 (35.1)
SF-36 Social Functioning	86.74 (20.6)	85.27 (21.2)	85.86 (20.9)

Benign Mental Health Consequences of Screening for Mutations of BRCA1/BRCA2

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Benign Mental Health Consequences of Screening for Mutations of BRCA1/BRCA2

Lodder et al. [2001] add to the growing body of data concerning the psychosocial impact of genetic screening for BRCA1/2 mutations. Importantly, theirs is the first study to focus on European women seeking genetic testing in the absence of a personal history of cancer, unlike many American studies that recruit women both with and without personal histories of cancer. As these authors observe, women with a history of cancer may have different motives for testing and view results as potentially confirmatory and, therefore, less threatening. Additionally, Lodder et al. include both women with recent knowledge of their familial cancer risk and women for whom this knowledge is longstanding. Previous investigators have often sampled women with prior involvement in familial cancer registries, calling into question the generalizability of their findings [Coyne et al., 2000].

Consistent with previous work [Audrain et al., 1997; Coyne et al., 2000], Lodder et al. indicate that, as a group, women anticipating genetic testing are not distressed, and that receipt of test results is not associated with substantial psychological morbidity, even when it reveals a mutation [Croyle et al., 1997; Lerman et al., 1996]. Like some past investigators, Lodder et al. do not fully explore the implications of these findings. Furthermore, there are aspects of their analysis and interpretation that invite perpetuation of a common misperception concerning the psychological risks associated with genetic testing for BRCA1/2 mutations.

In the Lodder et al. [2001] study, two self-report measures are used to assess distress, the Impact of Events Scale (IES) [Horowitz et al., 1979] and the Hospital Anxiety and Depression Scale (HADS) [Zigmond and Snaith, 1983]. As used in this study, however, the interpretation of each is problematic.

The IES is widely used as a cancer-specific measure of distress, and is intended to measure intrusive thoughts and avoidant behavior resulting from trauma. Lodder et al. [2001] report mean scores considerably lower than the commonly used clinical cut-point of 19 [Horowitz et al., 1979]. These findings may best be interpreted as "actively dealing with the problem" [Dudok de Wit et al., 1997] or active cognitive processing [Creamer, 1995] of the significance of the results testing rather than maladaptive thoughts or "traumatization."

The HADS [Zigmond and Snaith, 1983], developed to assess depression and anxiety among patients in a hospital setting, contains many items that seem to represent understandable responses to anticipation of test results, rather than psychiatric symptoms. (e.g., negatively scored items such as "I can laugh and see the funny side of things" and "I feel cheerful"). The standard cutoff score of 11 yields substantial rates of false positive identification of psychiatric disorder, even among groups of cancer patients with higher rates of psychiatric morbidity [Hopwood et al., 1991; Ibbotson et al., 1994]. Psychiatric morbidity among cancer-free women anticipating genetic screening is much lower [Coyne et al., 2000]. Thus, a cutoff of 11 is even less likely to indicate psychiatric disorder in this population. Nonetheless, Lodder et al. [2001] used a lower cutoff of 8 for the anxiety and depression subscales, and still obtained prevalence estimates of only 12% for "depression" and 20% for "anxiety." These rates did not differ between mutation carriers and non-carriers.

Reference to comparison data is important in resolving the significance of these results. Like other investigators, Lodder et al. [2001] do not include a comparison group of women who are neither known to be at high risk for cancer nor contemplating genetic testing. Without such a group, it is unclear whether any risk of distress is attributable to genetic testing. Elevated scores on self-report measures of distress are common in nonpsychiatric settings, reaching upwards of 35% in primary care settings [Fechner-Bates et al., 1994; Schulberg et al., 1985]. We believe that the rates of distress observed by Lodder et al. are what would be expected in a medical setting even in the absence of genetic testing, and caution against attributing such distress to the experience of genetic testing. Lodder et al.'s finding that, regardless of mutation status, distress is stable from pre-screening to post-results is consistent with this interpretation.

Appreciating the implications of these findings is made more difficult by the analyses used to demonstrate change in distress levels across time for women defined as having "high" or "low" anxiety. Most importantly, what is lost is that the assigned cutoff of 5 for "high" anxiety is well below any validated or clinically meaningful value, and the observed changes in anxiety are minimal.

The lack of attention to issues such as these is common practice in psychological studies of genetic screening, and we do not wish to single out Lodder et al. for criticism. We believe, however, that these data need to be interpreted accurately so that they add to the accumulating evidence that genetic testing for BRCA1/2 does not pose significant mental health risks. Women's response to the offering of genetic screening should not be construed primarily in psychiatric terms.

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Over-emphasis of psychological risks of genetic testing may have "dire" consequences

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Over-emphasis of psychological risks of genetic testing may have "dire" consequences

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Horowitz et al. (1) caution that clinicians should be aware of the likelihood of patients' adverse reactions to receipt of genetic testing for risk of cancer and other late onset diseases. Until recently, there had indeed been widespread concerns about what Horowitz et al. deem "turbulent, emotional reactions" resulting from genetic testing, and it was suggested that the risk of traumatization be weighed against the potential benefits of undergoing testing for decision making purposes. However, the theory, predictions, and vivid clinical examples presented by Horowitz et al., and the dramatic title to their article, are inconsistent with accumulating data indicating that genetic testing does not typically carry "dire" consequences. (2) One reason why patients fare better than had been expected may be that individuals pursuing genetic testing already know that they are at increased risk of disease on the basis of family history or ethnicity. Genetic testing may provide resolution to a larger stress process in which individuals have extensive family experience with illness and pre-existing concerns about personal risk. Testing may thus be a valuable tool for making decisions relevant to risk management. Most individuals undergoing genetic testing cope well with the results, and most distress resolves quickly. (2) Even among those receiving confirmation that they are mutation carriers, distress levels tend to decrease shortly after testing. (3)

A recent review of the psychosocial consequences of genetic testing concludes that whether individuals are found to carry a risk-conveying mutation is "rarely predictive of distress more than one month after testing." (2, p. 731) Furthermore, in contrast to test results, pretest psychological functioning does predict long term posttest emotional outcomes. (2-4) Taken as a whole, these data suggest that neither testing itself nor confirmation of positive mutation status pose significant psychological risks. Moreover, given that psychological outcome is dependent on pretest functioning, it is reassuring to note that psychiatric disorder and levels of distress among individuals choosing to undergo genetic testing are, on the whole, low and within the range expected in community samples. (2-5) There may well be some self-selection for psychological resources in the decision to move forward with testing. (4)

We do not wish to trivialize the significance of individuals' decision concerning whether to obtain genetic testing. Yet, such decisions need to be placed in their proper perspective, and it is important that we not preemptively make interest in testing a mental health issue. Professionals' focusing on the exaggerated risk of "dire" consequences of testing may unnecessarily frighten patients and deter them from making a reasoned decision weighing the balance of costs and benefits of knowing their status. It would be a mistake to maintain the inaccurate conception of genetic testing as a traumatic experience or over-emphasize the likelihood of "stress-response syndromes" resulting from testing. Focusing our attention on these unlikely outcomes potentially diverts limited resources from educational counseling and decision aids that are likely to have a greater value on a population basis than the requirement of psychological screening or follow-up with specialized mental health services.

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CHARACTERISTICS OF WOMEN WHO CHOOSE TO RECEIVE RESULTS OF GENETIC TESTING FOR CANCER RISK

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Not all women who undergo genetic testing for cancer risk choose to receive their test results. We examined the psychological and social functioning, reasons for undergoing testing, and perceptions of future cancer risk in a sample of high-risk women (n=40) who were offered and accepted their results. Most of the sample (92%) had a history of cancer diagnosis. The main reasons for undergoing testing included to estimate the risk that may be transmitted to their children (68%), to reduce uncertainty (48%), to plan for the future (38%), and to make decisions about whether to undergo prophylactic surgery (30%). Participants generally reported low levels of psychological distress on the Hopkins Symptom Checklist-25, with only 18% of the sample scoring above the clinical cutoff of 44. Overall, participants reported satisfactory interpersonal relationships, with high rates of positive and low rates of negative support from their spouses, female family members, and friends. Nearly half of the sample believed they had a risk of 10% or less of developing breast cancer again or of their cancer metastasizing in the near future. One third believed that their lifetime risk of recurrence or metastasis was 10% or less. Women in our sample who chose to receive the results of genetic testing generally had low rates of psychological distress, strong support from their social network, and most believe that the risk of their cancer recurring in the future is relatively low.

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MARITAL SATISFACTION IN THE LONG-TERM PHYSCIAL AND PSYCHOLOGICAL ADAPTATION OF WOMEN TO BREAST AND OVARIAN CANCER

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The experience of cancer and treatment confronts individuals with physical and emotional challenges. Adaptation to these challenges may be facilitated or inhibited by both physical and interpersonal factors. We examined physical and emotional outcomes in a sample of women (n=115) with a history of breast or ovarian cancer who were enrolled in a hereditary cancer registry. Participants had a mean age of 48.7 years. Intensity of treatment was assessed via the number of different treatment protocols participants underwent. Distress was assessed using the Hopkins Symptom Checklist-25, and overall functioning was assessed with the SF-36 Health Survey. Participants typically reported undergoing 2-3 medical protocols in the treatment of their cancer. Although assessment took place an average 7 years after diagnosis, treatment intensity continued to predict interference in functioning due to bodily pain ($p < 0.05$) and marginally predicted limitations in physical role functioning ($p = 0.08$). Better marital adjustment (DAS) predicted decreased psychological distress ($p < 0.00$), and more positive outcomes in terms of general health functioning ($p < 0.00$), vitality ($p < 0.01$), mental health ($p < 0.00$), emotional functioning ($p < 0.01$), social functioning ($p < 0.01$), and physical role functioning ($p < 0.01$). Better marital adjustment marginally predicted better outcomes with pain ($p < 0.07$) and overall physical functioning ($p < 0.09$). These relationships remained significant after controlling for both treatment intensity and time since diagnosis. Results add to the increasing body of evidence concerning the important role of social relationships in long-term adjustment to cancer.

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RUNNING TITLE: Numeric, qualitative, and comparative risk perception

Comparison of numeric, qualitative, and comparative measures of breast cancer risk perception.

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ABSTRACT

Perception of breast cancer risk is thought to be an important determinant of health-care

decision-making, screening behavior, and psychological distress among women with family

histories of breast cancer. Cancer risk counseling aims to assist women in accurately estimating

their risk. Published guidelines currently suggest that cancer risk counseling convey numeric

estimates of risk rather than ambiguous qualitative estimates, although women seem to be more

accurate in estimating their qualitative risk than their numeric risk. The current study compared

numeric, qualitative, and comparative risk estimates, and the relationship of these estimates to

cancer-specific distress. Women attending a high-risk cancer clinic (n=248) completed mailed

surveys after receiving cancer risk counseling. Surveys assessed breast cancer risk perception as

a percentage (numeric), as a Likert-type scale from low to high (qualitative), and compared to

the average woman (comparative), as well as distress assessed by the IES, and other health

services issues. Women significantly overestimated their numeric risk relative to objective risk

estimates, but did not appear to overestimate greatly their qualitative or comparative risk.

Additionally, on average women reported moderate levels of cancer-specific distress, and all

three measures of risk perception were equally related to distress. Taken together, these results

suggest that cancer risk counselors may be mistaken in relying solely on numeric risk estimates

for conveying risk or assessing risk perception, and that overestimation of numeric risk does not

necessarily indicate debilitating psychological distress.

INTRODUCTION

Risk perception figures heavily in the cancer risk counseling of women with family histories of breast cancer, and in the assessment of counseling effectiveness. Accuracy in a woman's perception of breast cancer risk is considered an important aspect of informed decision-making, and an antidote for excessive psychological distress[1]. Additionally, the accuracy of participants' estimates of their risk of developing cancer obtained after counseling is often used as an indicator of counseling effectiveness.

The two most common methods of estimating objective breast cancer risk are models developed by Gail[2] and Claus[3], both of which express risk in terms of a numeric probability or percentage. Published guidelines for genetic counselors emphasize the importance of communicating numeric risk[4], and caution against the use of qualitative estimates of risk that might impose the counselor's values or otherwise violate a participant's self-determination[5,6].

The assumption underlying the use of numerical probability estimates is that counseling participants understand probability estimates, and that these provide a value-neutral scaling system for communicating risk. However, there is ample evidence that many people have difficulty interpreting quantitative data such as probabilities, which requires a cognitive ability termed "numeracy". For example, one study of women with a family history of breast cancer found that over 90% of women overestimated their numeric risk of developing breast cancer relative to objective Gail estimates, and that 66% of these women "extremely overestimated"

their risk[7]. A study by Schwartz[8] found that a sample of female veterans performed poorly on numeracy tasks, and that the majority of women were unable to interpret numerical data about the reduction in risk of breast cancer death associated with use of mammography. Women with higher numeracy scores more accurately estimated the average risk of dying from breast cancer, and were better able to interpret numerical data about risk reduction. Another community study[9] and a review by Woloshin et al.[1] report similar findings regarding poor numeracy, and the association between numeracy and accuracy of risk perception.

An alternative to percentage estimates of risk are measures such as one's risk on a continuum from low to high, or one's qualitative risk relative to the average woman (comparative). Although the prevailing philosophy in cancer risk and genetic counseling has been to avoid such qualitative estimates of risk, such conceptions of risk may be important in participants' comprehension of risk. For instance, the finding that participants in cancer risk counseling have difficulty interpreting numeric probabilities, even after counseling that provides accurate risk estimates[7,10], suggests that risk is not simply a numeric construct for participants. Additionally, in comparing studies employing numeric or qualitative measures of risk perception, Woloshin, et al.[1] concluded that respondents were more accurate in estimating qualitative risk than they were in estimating quantitative risk.

The present study examined the concordance of numeric risk estimates to qualitative and comparative estimates among women who had received counseling concerning their personal

risk of breast cancer. A high concordance among these measures would suggest that different ways of assessing risk tap into a common risk perception construct. This study also compared numeric, qualitative, and comparative risk estimates to objective calculations of risk provided in pre-test counseling. Based on the results of previous research, we expected that numeric risk estimates would be less related to objective risk estimates than were the other risk measures because of likely overestimation of numeric probabilities. Finally, this study examined the degree to which different measures of risk perception were related to breast cancer-specific distress, one indicator of the utility of a particular measure of risk perception.

METHOD

Participants

A total of 248 women attending the Cancer Risk Evaluation Clinic for assistance in evaluating and managing their cancer risk participated in the present study. The average age of participants was 53 years (SD = 10.58), ranging from 21 to 88 years. Most participants were married (81.2%), Caucasian (71.7%), and college-educated (72.1%). About one-third had a personal history of breast cancer (27.9%).

Women attending the Cancer Risk Evaluation Program (CREP), a clinic for the assessment and management of cancer risk, were recruited for this study. The majority of women come to the CREP clinic intending to get genetic testing, and testing is available to any woman who requests it, although not all women choose to proceed with testing after counseling

Measures

Risk perception. Women were asked to estimate their chances of developing breast cancer at some point in their lifetime using three different measures: 1) a visual analog scale ranging from 0 to 100% chance of developing breast cancer (numeric); 2) a 5-point Likert-type scale ranging from very low to very high chance (qualitative); and 3) a 5-point Likert-type scale ranging from much lower to much higher chance compared to the average woman (comparative). These represent the most common types of risk assessments used in previous studies[1].

Objective risk. Estimates of objective risk were calculated from participants' pedigrees collected as part of standard clinic practice, and based on the Gail, et al model[2]. Gail risk estimates take into account the number of first- and second-degree relatives affected with breast cancer, and the age of cancer occurrence.

Cancer-specific distress. The intrusion subscale of the Impact of Event Scale[11] served as a measure of cancer-specific psychological distress. Items were modified to assess intrusive thoughts about breast cancer. For example "I had waves of strong feelings about it" became "I had waves of strong feelings about breast cancer". The authors report good internal consistency for the intrusive subscale, with coefficient alphas for two validation samples averaging .86.

Procedure

A total of 515 women received genetic counseling at the CREP clinic between January, 1995 and April, 1998. Of those 515, 137 were excluded from the survey due to a prior diagnosis

of cancer, and 28 declined participation in research. The remaining 350 women were mailed

surveys, 28 of which were returned due to bad addresses, and 3 because the potential participant

was deceased. A total of 248 surveys were returned, yielding a total response rate of 71%. All

participants completed the survey after cancer risk counseling. Women who chose to have

genetic testing completed the survey after receiving their test results and post-test counseling.

The average length of time between initial cancer risk counseling session and completion of the

follow-up survey was approximately 15 months. Neither risk perception nor psychological

distress varied systematically by time from the initial counseling to completion of the follow-up

survey.

RESULTS

Objective risk and subjective risk perception

Based on the Gail model of estimating prior probabilities for developing breast cancer,

the average lifetime risk of breast cancer for this sample was 26.0% (SD = 17.4). Compared to

the generally-accepted estimate of 11% lifetime risk of breast cancer in the general population,

the women seeking help from the CREP high-risk clinic were indeed estimated to be at higher-

risk.

As expected based on previous reports of numeric overestimates[7,12], women in this

sample largely overestimated their lifetime numeric risk, averaging 49.1% (SD = 32.7). A paired

t-test yielded a significant difference between objective risk estimates and numeric risk

perception ($\underline{t}$ = -8.07, $\underline{p}$ < .001), illustrated in Figure 1.

Using the qualitative and comparative risk measures, however, women's estimates of

their risk did not appear to be large overestimates. On a 5-point Likert scale, women estimated

their risk to be an average of 3.45, or about midway between the anchor points "Neither high nor

low" and "Moderately high". Similarly, women estimated their risk compared to the average

woman to be about 3.91 (SD = .90), just below "Somewhat higher" than the average woman.

Thus, participants seem to overestimate greatly their numeric risk, but not their qualitative or

comparative risk estimates.

Risk perception and breast cancer worry

Women reported an average of 13.3 (SD = 6.14) on the intrusion subscale of the Impact

of Event Scale[11]. According to the scale norms suggested by the authors[13], women in this sample

reported intrusive thoughts that are related to moderate levels of psychological distress.

Correlations between intrusive thoughts about breast cancer and risk perception were similar

across the three different measures. Examining the sample of women who provided all three risk

estimates (n = 163), correlations between risk estimates and breast cancer-specific worry were

similar, ranging from $\underline{r}$ = .32 to $\underline{r}$ = .38, all significant at $\underline{p}$ < .001,

IES scores were not significantly related to marital or employment status, or to ethnicity,

but were significantly higher for women without a college education ($\underline{t}$ = 3.75, $\underline{p}$ < .000), and for

women with a personal history of breast cancer ($\underline{t}$ = -2.72, $\underline{p}$ = .007). Accounting for breast

cancer status and education by entering these first into each of three hierarchical regression

equations predicting IES from risk perception did not significantly change the results.

DISCUSSION

The data from the current study show that although women largely overestimated

numeric probabilistic risk, they did not appear to largely overestimate qualitative and

comparative risk. In isolation, and contrary to the prevailing philosophy in risk counseling, this

result might suggest that qualitative risk estimates are a more accurate indicator of breast cancer

risk perception. However, all three estimates of risk were equally related to breast cancer-

specific worry. This suggests that although numeric risk estimates may be inflated relative to

objective estimates, numeric scales are likely to provide different, rather than inferior or superior,

risk perception information than qualitative estimates.

The finding that women seemed to overestimate numeric risk more than qualitative risk is

consistent with results reported by other researchers, and supports the findings from the only

other published comparison of numeric and qualitative estimates among the same women[1].

However, several limitations of the current study require that these results be viewed as tentative

pending replication. First, because of the metric of qualitative measures of risk perception, it is

difficult to compare precisely the degree of risk overestimation made using qualitative measures

to those made using a numeric measure. Second, the observed overestimation of numeric risk

may be due to limitations in numeracy, or to lack of understanding of the risk of the average woman, rather than to some fundamental difference in risk perception. Inclusion of a numeracy assessment, or an assessment of participants' estimates of the average woman's risk of breast cancer would have allowed more thorough analysis of these alternative hypotheses.

Limitations notwithstanding, these results have implications for genetic counseling. If counselors view risk based on objective, numeric estimates, and counselees tend to overestimate numeric risk, the discrepancy between counselor and counselee perceptions of risk may lead to misunderstandings. For example, Schwartz, Rimer, Daly, et al.[14] report that less-educated participants receiving individualized breast cancer risk counseling were less likely to adhere to mammography screening recommendations than more educated participants, suggesting that perhaps the individualized interventions misspecified how women perceive their risk. This discrepancy in conceptualizing risk also may explain in part why inaccurate estimates persist even after cancer risk counseling in which accurate estimates are provided[7].

Additionally, counselors may assume that overestimation of cancer risk signals risk for psychological distress, and that accurate numeric risk information is an antidote for apparent catastrophizing about breast cancer risk. However, despite the large overestimates of numeric risk reported by women in this sample, they did not report high levels of psychological distress, and distress was equally, although only moderately, related to all three measures of risk perception.

Taken together, the data from this study suggest that numeric probabilistic estimates of breast cancer risk should be seen as one of several indicators of breast cancer risk perception, rather than as a gold-standard measure. As such, relying solely on numeric risk estimates, either in conveying risk information, or in assessing risk perception, is likely to provide an incomplete view of a woman's sense of her breast cancer risk.

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Table 1

Intercorrelations Among the Numeric, Qualitative, and Comparative Risk Measures.

Subscale	1	2	3
1. Numeric Risk (Percentage)	--	.67**	.26**
2. Qualitative Risk (5-Point, Likert-type Scale)		--	.65**
3. Comparative Risk (Compared to the Average Woman)			--

** p < .001

Validity and Efficiency of Screening for History of Depression by Self-Report

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Because of the recurrent nature of depression, there is a need for a rapid means of screening for history of depression that is either valid in itself or an efficient means of identifying respondents needing further assessment. This study examined the validity and efficiency of assessment of lifetime history of depression by self-report screening questions in comparison with the results of a structured interview assessment conducted a year earlier. Self-reported lifetime 2-week mood disturbance was unrelated to the results of the earlier interview. Self-report of treated episodes of mood disturbance were related to interview-assessed history of depression, but too modestly for practical applications. Self-report of past depression was more strongly related to concurrent distress than to the earlier interview assessment of history of depression. Implications of these findings for screening and assessment of history of depression are discussed.

It is increasingly apparent that major depression is a highly recurrent, episodic disorder (Frank & Thase, 1999; Judd, 1998). Consequently, a history of depression has emerged as an important variable for risk stratification in both clinical practice and research. Depression occurs relatively rarely in single episodes across a lifetime (Keller, Lavori, Lewis, & Klerman, 1983), and a prior episode of depression is an important predictor that someone will become depressed in the future (Coyne, Pepper, & Flynn, 1999). In an adult population, first episodes of depression are infrequent, and it can be inefficient to track them prospectively. Thus, Eaton et al. (1997) found that when persons with prior histories of depression were eliminated from consideration, 23,698 person-years of study yielded only 71 new cases of major depression in 12- and 15-year follow-up assessments of participants in the Baltimore site of the Epidemiologic Catchment Area (ECA) study.

In a 12-year prospective study of more than 400 depressed patients seeking treatment in psychiatric treatment settings, Judd et al. (1998) found that they spent 15% of this time meeting full criteria for major depression and an even greater proportion of time with depressive symptomatology below the threshold for major depression. The risk for depression associated with prior episodes is also so high that the Agency for Health Care Policy Research Depression Guidelines (Depression Guideline Panel, 1993) now recommends indefinite maintenance treatment with antidepressants for persons with three or more episodes.

It is now recognized that most depressed individuals do not receive treatment (Depression Guidelines Panel, 1993), and that even individuals who obtain treatment may have needlessly suffered for months before seeking help (Monroe, Simons, & Thase, 1991). Increasing the detection of untreated depression in the community and in primary medical care settings has been designated a major public health priority (Regier et al., 1988). There have also been calls for strategies to identify people who are presumed to be at risk for depression because of current distress, with the hope that preventive intervention could allow the suffering, personal impairment, and social costs associated with the disorder to be averted altogether (Munoz, Hollon, McGrath, Rehm, & Vandenbos, 1994). The routine use of brief self-report measures has been seen as a key means of increasing detection of individuals who are either depressed and not receiving treatment or who are at imminent risk of becoming depressed (Munoz, Le, & Ippen, 2000). However, proposed screening instruments such as the Center for Epidemiologic Studies—Depression Scale (CES–D; Radloff, 1977) and the Brief Symptom Inventory (BSI; Derogatis, 1993) are best construed as measures of general distress. They are too nonspecific and, therefore, too inefficient to provide a cost-effective means of identifying depressed and at-risk individuals (Coyne, Thompson, Palmer, Kagee, & Maunsell, 2000). After extensive review, the United States Preventive Services Task Force (1996) and the Canadian Task Force on the Periodic Health Examination (1990) have recommended against the routine use of such instruments to screen for depression.

Given the recurrent nature of the disorder, however, tracking individuals with histories of depression might prove to be more efficient than mass screening for current distress as a means of identifying at-risk and depressed individuals. Theory and research examining psychosocial factors in depression have only begun to take into account the overriding importance of prior episodes for subsequent development and current psychological functioning. The bulk of previous psychological theorizing has focused on the psychosocial factors that contribute to a person becoming depressed. Yet, depressed persons typically have already suffered

numerous episodes of depression by the time they become available for study. Coyne et al. (1999) found that depressed research participants recruited from both primary medical care and outpatient psychiatric settings already averaged over eight previous episodes of depression. The likelihood that few episodes of depression under study are first episodes requires attention to the direct, mediating, and moderating effects of past episodes of depression on current psychosocial circumstances and resources. For example, Coyne and Benazon (2001) reviewed a number of effects of history of depression on marital functioning. People with a history of depression are less likely to be currently married than are people without a history (41.1% vs. 52.3%; Fredman, Weissman, Leaf, & Bruce, 1988). If they are married, their first episode of depression is likely to have preceded their marriage (Brisco & Smith, 1973; Bruce, 1998), and they are substantially more likely to have a history of divorce (odds ratio = 1.7; Kessler, Walters, & Forthofer, 1998). Many psychosocial predictors of depression lose their significance once prior episodes of depression are taken into account. Kessler and Magee (1994) found that this was the case for 13 of the 14 risk factors they examined. This suggests the possibility that psychosocial factors may affect the timing of first episodes of depression without affecting the overall lifetime risk. Thus, childhood adversity may hasten a first episode of depression, which ultimately would have occurred in the absence of such adversity (Coyne & Benazon, 2001).

The recognition of the importance of history of depression focuses attention on the need for valid and efficient means of screening for or assessing history of depression. A fundamental issue is whether a simple set of screening questions about prior depression is either valid in itself or an efficient means of identifying respondents in need of further assessment. Such quick and economical assessment strategies are increasingly desirable because of constraints on time and resources, but there are many reasons to believe that the task of assessing past depression may be more difficult than assumed. Efforts to identify current major depression by self-report have proven unsatisfactory; even when questions directly inquire about criterion symptoms (Zimmerman & Coryell, 1987), correspondence with semistructured interview is poor (28.5% positive predictive value; Fechner-Bates, Coyne, Schwenk, 1994; for a review, see Coyne, 1994). Indeed, even diagnoses of current disorder based on questions administered by lay interviewers have only a modest correspondence to results of a semistructured interview administered by a professional (Anthony et al., 1985).

Efforts to identify past episodes of depression are further complicated by problems of recall and the likelihood that respondents do not conceptualize relevant experience as a depressive episode with the same criteria as professionals would use. Problems in the reporting of past psychopathology are demonstrated in findings that a third of persons who had been hospitalized for a psychotic disorder did not report this when they were assessed 11 years later (Pulver & Carpenter, 1983). However, a more recent study found that 25 years after an initial assessment, 70% of a sample of depressed individuals recalled having 2 weeks of mood disturbance in the index period and 52% recalled enough symptoms to merit a retrospective diagnosis of major depression (Andrews, Anstey, Brodaty, Issakidis, & Luscombe, 1999). There also has been evidence of inaccuracy in the ascertainment of history of depression in epidemiologic surveys (Aneshensel, Estrada, Han-

sell, & Clark, 1987; Rice, Rochberg, Endicott, Lavori, & Miller, 1992). This may explain the paradox that lifetime reported rates of depression decline with age despite the expectation that they should increase because older persons have been at risk longer than younger persons (Robins, 1985). Perhaps, even more troubling is Dohrenwend's (1989) finding that 61% of the respondents who reported past major depression at baseline in the ECA study did not do so a year later. Aside from issues of recall, it may be that many persons do not construe an episode of depression as a discrete episode of disturbance. When depressed persons present to physicians, most do not identify themselves as depressed (Coyne, Schwenk, & Fechner-Bates, 1995).

The present study examined whether responses to simple inquiries concerning history of depression, which were embedded in a self-report instrument, corresponded to diagnoses of past depression that had been elicited in a semistructured diagnostic interview a year earlier. A straightforward question concerning whether the respondent had ever experienced a 2-week period of mood disturbance was evaluated alone and in combination with questions of whether, if a mood disturbance had ever occurred, it impaired interpersonal relations or had been treated with therapy or medication. The null hypothesis of no relation between the inquiry concerning mood disturbance and results of the diagnostic interview strains credibility. Yet, the important question is not whether a statistically significant association can be found, but whether the simple inquiry is valid and clinically efficient. With sufficient sample size, it is possible to obtain a highly significant statistical association even when the absolute level of agreement with a criterion variable is so low as to make the use of a screening approach inefficient and impractical.

The relation between a simple inquiry and results of a clinical interview can be expressed in terms of the positive and negative predictive values and sensitivity and specificity of the inquiry concerning mood disturbance (Fletcher, Fletcher, & Wagner, 1988; Zarin & Earls, 1993). *Positive predictive value* (PPV) refers to the proportion of persons who respond affirmatively to the self-report inquiry who have a history of depression. *Negative predictive value* (NPV) refers to the proportion of persons who respond in the negative to the self-report inquiry who do not have a history of depression. *Sensitivity* refers to the proportion of persons with a history of depression who answer affirmatively to the self-report inquiry concerning mood disturbance. *Specificity* refers to the proportion of persons without a history of depression who respond in the negative to the self-report inquiry. Both PPV and NPV depend upon the prevalence of the disorder, as well as the specificity and sensitivity of the inquiry (Fletcher et al., 1988).

It may be unrealistic to assume an excellent correspondence between a short set of screening questions concerning history of depression and the results of a more systematic interview. Yet, such questions might still be efficient as a first step in a two-stage assessment procedure if the inquiry has good sensitivity, even if it has poorer specificity (Newman, Shrout, & Bland, 1990). With appropriate weighting of the resulting data, such a two-stage procedure would actually produce more accurate estimates of the prevalence of history of depression than the performance of the same number of interviews with an unscreened sample of the same size. For clinical purposes, a screening for history of depression could be useful even with less than optimal sensitivity, if it has good PPV. A clinician who received an affirmative answer from a

patient concerning a history of depression could presumably be confident that the patient had been previously depressed, even if a concern remained that significant numbers of patients with such a history were being missed with such a strategy. However, our evaluation of the PPV, NPV, sensitivity, and specificity of inquiries concerning history of depression ought to be qualified by any evidence of systematic biases in the responses to such inquiries. For instance, it would be problematic if patients' recall of past depression was found to be unduly influenced by their current psychological state, a possibility we examined in this study. Such a finding would raise troubling questions about the validity of the inquiry concerning past depression, even in the context of a positive agreement with a criterion interview-based assessment of prior depression.

Method

Sample and Recruitment Procedure

The sample consisted of 323 women who were drawn from the registry of the Hereditary Breast and Ovarian Cancer Study (HBOCS) that was conducted by the University of Michigan and the University of Pennsylvania Cancer Center. The HBOCS has resulted in a number of empirical findings, and its methodology is reported in more detail elsewhere (see Coyne & Anderson, 1999; Coynè, Benazon, Gaba, Calzone, & Weber, in press). The initial measure of self-reported distress and diagnostic interview data reported in this article are derived from baseline assessments obtained from these women starting in the year after the announcement that a strong candidate for the breast and ovarian cancer susceptibility gene, BRCA1, had been identified (Miki et al., 1994). At the time of the baseline assessment, the offering of genetic testing to these women for risk of breast and ovarian cancer was widely expected to be imminent. There were concerns that high-risk status would confer vulnerability to distress and depression upon these women and that this would interfere with their ability to participate in informed consent about receiving these results. There was also a need to obtain baseline data so that any psychological effects of subsequent testing could be identified.

Women who enrolled in the registry were asked to complete a baseline questionnaire including a measure of distress, a 25-item version of the Hopkins Symptom Checklist (HSCL-25; Hesbacher, Rickels, Morris, Newman, & Rosenfeld, 1980). They then received a telephone interview including the mood disorders, anxiety, and alcohol-use modules of the Structured Clinical Interview (SCID; First, Spitzer, Williams, & Gibbon, 1995) for the *Diagnostic and Statistical Manual of Mental Disorders* (4th ed., *DSM-IV;* American Psychiatric Association, 1994). Over the course of the next year, it became apparent that as a result of technical and logistical problems, it would still not be possible to offer many of these women information about whether or not they carried a mutation of BRCA1 conferring increased risk for cancer. An interim 1-year assessment of women who had not yet received results of genetic screening was, therefore, introduced to monitor psychosocial and mental health variables that might be subject to change in the intervening period. This assessment by a mail-back self-report questionnaire packet included the HSCL-25 and the queries concerning past depression used in the present article.

Measures

Depression screening questions. The inquiry concerning past depression started with a question taken directly from the Diagnostic Interview Schedule (DIS; Robins, Helzer, Croughan, & Ratliff, 1981) and assessed 2-week mood disturbance and associated impairment. The first question was,

Have you ever in your life had two weeks or more when, nearly every day, you felt sad, blue, or depressed *or* in which you lost all interest in things like work or hobbies or things you usually liked to do for fun?

If there had been such a period, three separate follow-up questions inquired (a) whether the respondent's work or relationships suffered, (b) whether the respondent had received counseling or psychotherapy, or (c) whether the respondent had received medication for this condition.

Rost, Burnam, and Smith (1993) had previously reported sensitivity in excess of .80 and specificity in excess of .90 for a pair of screening questions that assessed current depressed mood and anhedonia with respect to a simultaneously obtained diagnosis of major depression using the DIS (Robins et al., 1981). Although these figures suggest some promise for these questions as a means of screening for depression, they may have been inflated by their direct correspondence to the questions in the DIS. Unlike the SCID (First et al., 1995), the DIS is basically a lay interviewer-administered questionnaire and does not allow for interviewer probes of responses (Coyne, 1994).

Psychological distress. The HSCL-25 was used to assess psychological distress. The scale includes 10 items from the 90-item HSCL (HSCL-90) anxiety cluster, 13 items from the depression cluster, and two additional somatic symptoms (poor appetite and difficulty falling asleep or staying asleep). The same items also appear with inconsequential differences in wording on the Symptom Checklist 90 (SCL-90; Derogatis & Cleary, 1977). Hesbacher et al. (1980) found that the HSCL-25 correlated highly (.73) with the standard 58-item version of the HSCL (Derogatis, Lipman, Rickels, Uhlenhuth, & Covi, 1974). The HSCL-25 has been widely used for the psychiatric screening of medical patients (Fink et al., 1995). With a cutoff of 44 for caseness, Hough, Landsverk, Stone, and Jacobson (1982) found that the HSCL-25 was comparable or superior to the CES–D (Radloff, 1977) in detecting psychiatric disorder, depending on the criterion used. Consistent with past studies, coefficient alpha for the HSCL-25 was found to be .91.

Interview-based measures of psychiatric morbidity. Semistructured interviews were conducted to assess current and past history of depression, anxiety, and alcohol use. Because of its modular construction, the SCID can be adapted for use in studies in which only a particular diagnosis is of interest (First et al., 1995). The SCID interviewers were given extensive training and were at least at a master's level, with most having a doctorate in clinical psychology. The administration of the SCID was done by telephone because many of the participants were from out of state. Previous studies have shown that the concordance of telephone-administered diagnostic interviews with face-to-face interviews for assessment of depression ranges from .7 to .99 (Baer, Brown-Beasley, Sorce, & Henriques, 1993; Potts, Daniels, Burnam, & Wells, 1990; Wells, Burnam, Leake, & Robins, 1988). Also, Slutske et al. (1998) recently showed that the reliability and validity of alcoholism diagnoses and symptoms by telephone assessment is as good as what is obtained in face-to-face interviews. Concurrent with the present project, we conducted a reliability study that compared interviewers' diagnoses and ratings of diagnosis and symptoms of depression to independent raters who used 28 audiotapes of telephone assessments. The interviewers included some of those who were employed in the present study, but the sample of interviewers and tapes was not limited to this study. There was 100% agreement for diagnosis. Although an interrater agreement study was not conducted for the present project, a concurrent study in the same laboratory found a kappa of .80 for lifetime diagnosis of depression.

Results

Basic Demographics

The women in the sample were in their late 40s (M = 49.9, SD = 12.2), and they were predominantly White (98.1%), Chris-

tian (80.3%), married (74.9%), and had an average of two children. One striking characteristic of this group is their high level of education and income. Most women had at least some college education, worked outside the home, and had an annual family income that exceeded $54,000. These results are consistent with previous findings that women who seek genetic testing are generally well educated and have a higher social economic status than representative women drawn from the general population (Codori, Hanson, & Brandt, 1994; Kash, Holland, Osborne, & Miller, 1995).

Women who reported a history of depression in the SCID interview were somewhat younger than those who did not report a history of depression (mean age = 46.6 years vs. mean age = 49.1 years; t = 2.07, p < .05, Cohen's d = .23). They did not significantly differ from those who did not report a history of depression on any other demographic variables (ethnic background, marital status, number of children, or education level).

Women who reported a history of depression in the simple self-report did not significantly differ from those who did not on a number of demographic variables. There were no significant differences in age, ethnic background, marital status, number of children, and education level between those women who reported a history of depression on self-report and those who did not.

Prevalence of Past History According to Semistructured Interview and Simple Self-Report

According to the semistructured SCID interview, 66 (20%) of the women had a history of depression. The simple self-report administered 1 year later, concerning past mood disturbance of at least 2-weeks duration, yielded a much higher number of women reporting a history of depression (179; 55%). Not only were the estimates of prevalence vastly different between semistructured interview and simple self-report, but there was not significant overlap between semistructured interview and simple self-report in terms of who had a history of depression and who did not, $\chi^2(1, N = 323) = 0.51$, ns, Φ = .04. The correspondence between self-report and structured interview of history of depression is shown in Table 1. Specificity for the simple self-report was a modest 44% and sensitivity was not much better (52%). PPV was only 19%, whereas NPV was high (78%), but this reflected the relatively low base rate of interview-detected depression. Interpretation of all these measures of performance must be qualified by noting that the relation between the screening question and

interviewer-assessed history of depression did not depart from chance. Thus, what might seem to be an impressive NPV is actually the same result that would be obtained by ignoring the screening and assuming that none of the women had a history of depression.

Effects of Including Impairment Criteria in Defining Past Depression

As noted earlier, the query about past history of depression was followed by three "If yes, ..." probes that provided multiple means of meeting an impairment criterion. The prevalence of reported past depression based on an affirmative response to the mood disturbance question and to any of the impairment questions was 38%. Affirmative response to any of the impairment probes increased sensitivity of report of past depression to 63% but reduced specificity to 43% with respect to the earlier interview. PPV remained modest (23%), and NPV was modestly improved (81%). The relationship between the qualified self-report and SCID-detected history of depression remained nonsignificant, $\chi^2(1, N = 316) = 0.90$, Φ = .05. An affirmative answer to the mood disturbance question and the probe "If yes, did your work or relationships suffer?" provided a prevalence of past depression of 33%. It increased specificity to 68%, and reduced sensitivity to 36%. PPV remained unchanged (23%), as did NPV (81%). The relationship between self-report of past depression qualified in this way, and SCID-detected history of depression remained nonsignificant, $\chi^2(1, N = 321) = 0.50$, Φ = .04.

The inclusion of only the more stringent "If yes, did you get counseling or psychological treatment?" qualifier provided a prevalence of past depression of 24%. It increased specificity to 78%, and reduced sensitivity to 34%. PPV was increased modestly (29%), and NPV remained relatively unchanged (82%). The relationship between self-report qualified in this way, and SCID-detected history of depression was significant but low in magnitude, $\chi^2(1, N = 318) = 4.13$, p < .05, Φ = .11. The inclusion of only the "If yes, did you get medication for this problem?" qualifier increased specificity to 86% and reduced sensitivity to 27%. PPV was increased modestly (32%), and NPV remained unchanged (82%). The relationship between self-report qualified in this way and SCID-detected history of depression was significant but low in magnitude, $\chi^2(1, N = 314) = 5.73$, p < .05, Φ = .14. The strength of this finding was driven by most women not having a history of depression; most of these women (85.7%) indicated

Table 1

Correspondence Between Self-Report and Structured Clinical Interview of History of Depression (SCID)

| Self-reported | SCID | | Total | |
	No history	History		
No history	112	32	144	NPV = 112/144 (78%)
History	145	34	179	PPV = 34/179 (17%)
Total	257	66	323	
	Spec. = 112/257 (44%)	Sens. = 34/66 (52%)		

Note. NPV = negative predictive value; PPV = positive predictive value; Spec. = specificity; Sens. = sensitivity.

that they had not had a 2-week mood disturbance for which they received medication. Thus, a statistically significant association was not the basis of a clinically useful screening tool, as can be noted from the phi coefficients.

Two of the qualifiers ("If yes, did you get counseling or psychological treatment?" and "If yes, did you get medication for this problem?") were combined to make up a help-seeking qualifier. Women who endorsed either counseling or medication use were considered to have reported help seeking. The help-seeking qualifier provided a past prevalence of 28%. It had a specificity of 74%, a sensitivity of 38%, a PPV of 27%, and an NPV of 82%. The relationship between self-report qualified in this way and SCID-detected depression was marginally significant, $\chi^2(1, N = 313) = 3.62, p < .06, \Phi = .11$.

Effects of Current Psychological State on Report of Past Depression

Women who reported a past episode of depression in the self-report inquiry were more likely to be distressed according to a concurrently administered HSCL-25 than were women who did not report prior depression, $\chi^2(1, N = 317) = 32.29, p < .001, \Phi = .32$. This result is presented in Table 2. In fact, the simple inquiry about history worked much better as a screen for distress than it did for SCID-assessed history of depression.

SCID-assessed history of depression also predicted current distress. Women who had reported a past episode of depression in the SCID interview were more likely to be distressed, according to a standard cut score of 44 on the HSCL-25, than were women who had not reported prior depression, $\chi^2(1, N = 315) = 13.78, p < .001, \Phi = .22$.

Finally, to examine the possibility that highly distressed women are sensitized to remember past episodes of depression, we examined the relationship between SCID-detected and self-report history of depression in women who had elevations above the cut score on the HSCL-25. There was no significant relationship between SCID-detected and self-report history of depression in this group of women, $\chi^2(1, N = 63) = 1.96, \Phi = .04$.

Discussion

This study sought to evaluate whether it is justifiable to use a simple retrospective self-report inquiry as an indicator of history of depression for clinical and research purposes. The self-report questions were compared to results of a semistructured diagnostic interview that was conducted a year earlier and to a concurrently

administered self-report measure of distress. We had set a number of criteria for evaluating the validity and efficiency of such self-reported history of depression. Specifically, with a sample of more than 300 women, the issue was not whether a statistically significant relation between self-report and the earlier interview would be found, but whether the PPV, NPV, sensitivity, and specificity of the self-report questions would be such that they could be applied validly and efficiently in clinical and research settings. Even if performance of the self-report did not justify its use to classify patients or research participants, it might still have been sufficient to serve as the first stage in a two-stage process of screening and follow-up interview. However, we not only found the performance of the self-report questions unsuitable for such applications, but we also unexpectedly failed to find more than a chance relation between the self-report questions and the earlier diagnostic interview. The exception to a pattern of null findings was a weak, but statistically significant, relationship between self-report of a lifetime mood disturbance for which treatment was sought and an earlier interview finding of a history of depression. Despite statistical significance, using this self-report of treated mood disturbance would result in considerable misclassification of patients or research participants. One of our disconcerting findings was that most women who were found to have a history of depression in the interview no longer reported a 2-weeks period of mood disturbance in their lifetime in an assessment by questionnaire a year later. This replicates findings reported by Dohrenwend (1989). Also troubling, we found significant relations between reports of a history of mood disturbance and concurrent distress. As an indicator of history of depression, at least by the criterion we had chosen, the self-report questions were not very useful and were potentially misleading.

Before we discuss potential implications of these findings, it is important to consider how some features of this study might be relevant to the strength and generality of the conclusions we might draw. First, there is the criticism that there is no "gold standard" for past history in this study; we only have a comparison between self-report and an earlier interview. Although the issues are complex, some credibility should be granted to this criticism. We cannot ascertain the validity of the interview assessment of past history, particularly when it is used to classify individuals. However, in many contexts, interview assessment is all that is possible, and it remains important to determine whether self-report can serve as an equivalent or a first-stage screening to select individuals to interview.

Table 2
Correspondence Between HSCL-25 and Self-Reported History of Depression

| Self-reported | HSCL-25 | | | |
	No distress	Distress	Total	
No history	162	15	177	NPV = 162/177 (92%)
History	93	48	141	PPV = 48/141 (34%)
Total	255	63	318	
	Spec. = 162/255 (64%)	Sens. = 48/63 (76%)		

Note. HSCL-25 = 25-item version of the Hopkins Symptom Checklist; NPV = negative predictive value; PPV = positive predictive value; Spec. = specificity; Sens. = sensitivity.

A second issue that could be raised involves the year between the interview assessment of history of depression and the self-report of history of mood disturbance that we attempted to validate against it. Could the development of distress and depression in this year explain the discrepancy between results of the interview and the later self-report of history of depression? A number of factors suggest that this was unlikely to be a major factor in the results that we obtained. First, the prevalence of current major depression at the first assessment was so low as to suggest that a quantum increase in incident depression would have been needed to create a substantial discrepancy between these earlier and later ascertainments of depression. Yet, in this same time period, there was no increase in mean psychological distress for the sample. Also, in this age range, first episodes of depression are relatively uncommon, so 1-year incidence could not be a strong influence on the self-report of history of depression. Finally, unpublished analyses of various measures of psychosocial factors that were collected in this time frame suggest that this was an uneventful year for most women in the sample. Therefore, depression or life events in the year between the interview and the self-report assessment may attenuate the relations we found but are unlikely to be the major determinants of the weakness of our results.

A third challenge to the validity and generalizability of the results is the fact that the self-report of history of depression concerned only 2 weeks of mood disturbance and not the additional symptoms needed for a diagnosis for depression. This could readily affect the specificity of the screening questions, but it should not affect their sensitivity, which was unacceptably low. Furthermore, the introduction of impairment criteria in the self-report should have compensated at least in part for the lack of assessment of additional symptoms of depression. Presumably, occurrence of a full syndrome of depression would be more strongly associated with impairment of interpersonal relationships and the receipt of treatment than would 2 weeks of mood disturbance without additional symptoms.

A fourth criticism of our study is the selectiveness of our sample. We studied a rather select sample of women, presumably at high risk of breast and ovarian cancer based on family history, while they were awaiting genetic testing that was potentially informative of their actual risk for cancer. Yet, a previous study of the larger registry from which the present sample was drawn revealed the women to be no more distressed than primary medical care samples and well within range of epidemiological findings for lifetime and current prevalence of depression (Coyne et al., in press). With respect to current distress and depression at the point of initial assessment, they were not an unusual group of women.

Another potential challenge to the validity of our findings is the fact that this screening instrument is very brief. The argument might be made that a longer assessment of recall of history of depression might provide more encouraging results. Although it is true that a longer instrument might perform better in terms of reliability, most multiple-response assessments of depression depend upon an affirmative response to these questions in order to be activated. Our results demonstrate the questionable nature of the assumption that people can remember past episodes of depression accurately without the guidance of a trained interviewer.

A final challenge to broad interpretations of the results that were obtained is that the questions concerning history of depression were embedded in a larger survey instrument and they may not have been given the careful reflection that they would have in other contexts, notably a clinical interview. We believe that, for some purposes, this is a valid criticism. There are reasons to believe that the results obtained with a self-report instrument could indeed be different from results obtained with the same instrument in the context of a formal interview or in the process of help seeking. For example, Helzer et al. (1985) suggest that making an appointment for treatment and talking with a clinician may trigger memories of past depression. The clinician–patient interaction may also serve to allay the patient's concerns about disclosing past depression, including fears of being stigmatized, thereby increasing disclosure. There are two empirically testable hypotheses being raised here. The first is that the clinical context enhances recall of history of depression, regardless of how this history is assessed. The second is that clinician–patient interaction may facilitate the disclosure of history of depression. These hypotheses deserve further investigation.

However, it is important for other purposes to note that individuals seeking treatment are a biased sample of all depressed persons, and the particular episodes of depression they recall also may be a biased sample. Selective filters that determine who seeks treatment for depression in specialty settings (Goldberg & Huxley, 1992) include severity of current depression, the course of current depression (including prior treatment), and the number and severity of past episodes of depression. Individuals who seek treatment are likely to have more severe episodes of depression to report, and they may selectively recall the most severe episodes. Issues of potential selection bias are confounded with issues concerning the differences in the characteristics of depression found in specialty mental health versus other settings. Episodes of depression reported by patients in mental health settings typically have lasted months or years, whereas episodes reported by individuals who are recruited from other settings tend to have lasted weeks or a few months.

Our results do not support use of questions concerning mood disturbance and impairment that are embedded in a larger survey either as a means to identify respondents as having a history of depression or as the first stage in selecting them for further interview assessment. It remains to be seen to what range of contexts and assessment strategies our disheartening results generalize. Even though administered by lay interviewers, instruments such as the DIS (Robins et al., 1981) may be susceptible to at least some of the problems encountered in our study. Such instruments are essentially interview-administered questionnaires and provide no opportunity for interviewers to explain questions or response options or probe responses. Furthermore, diagnosis of current depression using the DIS depends upon first establishing lifetime depression, and this, in turn, depends on answers to the same questions concerning lifetime 2-week mood disturbance that were used in our study. Using DIS data from the ECA study, Kessler and McGee (1994) reported an odds ratio close to 40.0 for prior depression predicting current depression in a community sample. Prospective studies also reveal that depression is highly recurrent (Judd et al., 1998). We are inclined to explain some of the extraordinary strength of Kessler and McGee's (1994) findings as being the result of a confounding of current mood disturbance with recall of past depression. Taken together with our findings, these results stand as a caution against uncritically accepting results of research where such biases may be operating.

History of depression is a crucial consideration in clinical practice and research, despite the difficulties we have shown in its assessment. One implication of our findings is that, wherever possible, use of records of past depression is to be strongly preferred over a reliance on respondent recall. For instance, the treatment of depression among primary care patients should be recorded in a way that allows ready identification of such patients in the future. Yet, given our results, what can we recommend for assessment of past depression in the many contexts where independent validation of respondent reports is not available? We also believe that the validity should be examined of a simple verbal inquiry concerning past depression made in the context of a supportive interview. Chochinov, Wilson, Enns, and Lander (1997) demonstrated the satisfactory performance of a simple inquiry of terminally ill medical patients concerning depressed mood and anhedonia with respect to results of a formal semistructured interview, as well as the superiority of this inquiry over self-report screening instruments. It is not clear whether the critical factor was the rapport that was established or the opportunity to discuss the questions and patients' responses. Regardless, such interview assessment of current depression may be more efficient than screening with self-report questionnaires (Coyne et al., 2000), and our results suggest that an even stronger case might be made for the interview assessment of lifetime depression, given the poor performance of self-report. Having set out to establish at least some modest usefulness to screening for history of depression using some simple queries on a self-report instrument, we are left instead in the position of advocating reliance on a clinical interview or relevant case records. However, before completely dismissing screening by self-report, the issue needs to be examined in a clinical setting where contextual factors might prime a more accurate recall of positive history of depression.

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Distress and Psychiatric Morbidity Among Women From High-Risk Breast and Ovarian Cancer Families

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This study assessed psychological distress and psychiatric disorder in high-risk women enrolled in a hereditary breast and ovarian cancer registry, and it evaluated the concordance between self-report data and interview-based psychiatric diagnosis. A sample of 464 women completed the Hopkins Symptom Checklist–25 and were interviewed using modules of the Structured Clinical Interview for DSM–IV. Level of psychological distress and the prevalence of psychiatric disorder were low and in the range that would be expected for a sample of community-residing women. Screening proved inefficient: Less than 10% of distressed women met criteria for a clinical disorder. High-risk women seeking genetic testing in research settings may not require extensive psychological screening and diagnostic assessment. Caution is expressed about possible self-selection biases in women enrolled in hereditary cancer registries.

The mapping of the human genome and the cloning of genes that convey risk for adult-onset diseases raises the possibility of increasingly widespread genetic testing. Consideration of the presumed benefits of genetic testing needs to be balanced by concerns about the psychological and psychiatric morbidity that could result from individuals being provided with potentially devastating information about future threats to their health. Testing will result in many individuals being burdened by the knowledge that they have an increased probability of developing a life-threatening disease long before its likely onset, and yet options for managing this risk are currently limited. Moreover, individual testing results may reveal that other family members are likely to have an inherited susceptibility to cancer, and this could prove to be an additional psychologically threatening prospect.

The need to understand psychosocial issues in genetic testing became more pressing with the cloning of the genes BRCA1 (Miki et al., 1994; Tavtigian et al., 1996) and BRCA2 (Wooster & Stratton, 1995), alterations of which are associated with many cases of early-onset breast and ovarian cancer. BRCA1 mutations

confer an increased risk for breast, ovarian, and prostate cancers. The lifetime risk of breast cancer for a woman with a BRCA1 mutation is in the range of 50%–85%. In women already diagnosed with a unilateral breast cancer, there is also an increased risk for developing disease in the contralateral breast. The risk of ovarian cancer approaches 20%–40% by age 80. BRCA2 mutations are similar to BRCA1 mutations in conferring a 50%–85% lifetime risk for breast cancer in women. The risk for ovarian cancer is lower than that associated with BRCA1, approximately 15%–20% over the lifetime. BRCA2 mutations also appear to be associated with other cancer risks, possibly including pancreatic cancer and other as yet undetermined sites (Ford et al., 1998).

It is estimated that as many as 1 in every 1,000 persons carries an altered gene associated with susceptibility to breast and ovarian cancer (Ford & Easton, 1995). Options for women who test positive for an altered gene include increased surveillance, prophylactic mastectomy, or oophorectomy and, for some, participation in a chemoprevention trial. None of these measures has proven to be entirely efficacious, and all have known limitations (Burke et al., 1997; King, Rowell, & Love, 1993). A retrospective study recently found that prophylactic mastectomy may reduce the incidence of breast cancer and death from breast cancer among high-risk women by as much as 90% (Hartmann et al., 1999). However, a closer look at this study highlights the uncertainty facing carriers of mutations of BRCA1 and BRCA2 in making decisions about how to manage their risk (Eisen & Weber, 1999). First, it is unclear to what extent the benefits observed in a heterogeneous sample of at-risk women extend to carriers of mutations of BRCA1 and BRCA2. It is likely that only a minority of the women in Hartmann et al.'s (1999) study were mutation carriers, perhaps as few as 10% (Couch et al., 1997). Second, in this study, 639 women electing prophylactic surgery resulted in a reduction of deaths only from an expected 20 to an observed 2. Saving 18 lives is important, but the

awareness that another 621 women would probably have survived without electing disfiguring surgery may make the choice of prophylactic surgery unacceptable to many women (Eisen & Weber, 1999).

Although genetic screening for risk of breast and ovarian cancer has become available commercially, it is still considered most appropriate for women who are already considered at high risk on the basis of family history because negative test results are not particularly informative for women without a known altered gene accounting for breast cancer in their families. Women with positive family histories have expressed considerable interest in being tested (Jacobsen, Valdimarsdottier, Brown, & Offit, 1997; Lerman et al., 1997; Lerman, Seay, Balshem & Audrain, 1995). To varying degrees, these women will have had experiences with cancer among their close female relatives, and their personal risk will have been made salient for them as they confront the opportunity to be tested. Many will already have a history of breast or ovarian cancer, and they will be seeking testing to determine the risk of cancer in the contralateral breast or in the ovary or to determine if their cancer is associated with an altered gene carrying heightened risk for other family members. Other women seeking testing will not have such a personal history of cancer but, on the basis of their high-risk status, already assume that they have the altered gene and that this is tantamount to having been diagnosed with cancer (Geller et al., 1995).

One key issue is the extent to which high-risk women's existing level of distress or vulnerability to major depression or other psychiatric disorders might impair their ability to become educated, make an informed choice about testing, and use their test results to manage their risk of cancer. There is now one study indicating that genetic testing does not lead to psychological distress, even when patients learn they have a mutation associated with heightened risk of cancer (Lerman et al., 1996). This finding is reassuring, but the research was limited to a distinct group of men and women who had a known genetic basis for the cancer in their families, and who had been participating in genetic studies for a long time. This research report also combined data from men and women in these high-risk families. Women, in general, have higher levels of distress than men, and they can also be expected to be more affected than men by anticipation of testing and receipt of information that they carry a gene associated with heightened risk for breast cancer. In the absence of much experience with women seeking genetic testing for risk of breast cancer, we are forced to draw on other relevant research, such as women anticipating a biopsy and women who have been diagnosed with breast cancer. Also relevant are studies of individuals learning their risk status for illnesses such as Huntington's disease (HD) and HIV.

There have been indications that some women who have a family history of breast cancer are psychologically distressed (Kash, Holland, Halper, & Miller, 1992; Lerman & Schwartz, 1993; Valdimarsdottir et al., 1995). Other studies suggest that women who are awaiting a biopsy because of suspected breast cancer are psychologically distressed (DeKeyser, Wainstock, Rose, Converse, & Dooley, 1998; Hobfoll & Walfisch, 1984). Moreover, several investigators have reported that women with confirmed diagnoses of cancer have elevated rates of clinical depression (e.g., Derogatis et al., 1983; Fallowfield, 1990; Goldberg et al., 1992; Hopwood, Howell, & Maguire, 1991; Maguire et al., 1978). In contrast, some investigators have reported low levels

of psychological distress and clinical depression among women with breast cancer (e.g., Plumb & Holland, 1981; Silberfarb, Maurer, & Crouthamel, 1980; Worden & Weissman, 1977). There have been historic changes in the social and health care milieu within which breast cancer is diagnosed and treated (Andrykowski et al., 1996) that may decrease the associated distress and psychiatric morbidity. Yet the lack of consistent findings in these studies is also undoubtedly due, in part, to the basic methodological weaknesses inherent in much of this research. To be specific, many of these studies involved small samples of women assessed either directly after diagnosis and surgery or during advanced stages of the illness (e.g., Goldberg et al., 1992; Hopwood et al., 1991; Maguire et al., 1978; Pinder et al., 1993; Silberfarb et al., 1980). In addition, researchers have typically relied on self-report assessment in determining psychiatric morbidity (e.g., Goldberg et al., 1992; Hopwood et al., 1991; Pinder et al., 1993). There is a need to distinguish between self-reported distress and interview-based diagnoses of psychiatric disorder (see Coyne, 1994, for an extended discussion). Elevated scores on self-report measures of distress, such as the Center for Epidemiologic Studies—Depression Scale (CES–D; Radloff, 1977), Beck Depression Inventory (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961), and various versions of the Hopkins Symptom Checklist (Derogatis, Lipman, Rickels, Uhlenhuth, & Covi, 1974; Hough, Landsverk, Stone, & Jacobson, 1982), consistently provide overestimates of the rates of diagnosable psychiatric morbidity. However, despite clarification of the distinction between distress and clinical depression (Massie & Popkin, 1998), the confusion of the two remains widespread in the psycho-oncology literature (for recent examples, see Keogh, O'Riordan, McNamara, Duggan, & McCann, 1998; Zittoun, Achard, & Ruszniewski, 1999) and the genetic testing literature as well (Lawson et al., 1997).

Studies of genetic testing for risk of HD and serological testing for HIV suggest that distress and development of psychiatric disorder are not necessary consequences of receipt of positive test findings. Negative emotional reactions may be transient except for some persons who were distressed before testing or who had a past history of depression (Perry, Jacobsberg, Fishman, & Frances, 1990). As in other contexts, current distress may predict later distress (Cramer, 1994; Kaplan, Roberts, Camacho-Dickey, & Coyne, 1987), and a history of depression is one of the most reliable predictors of future risk of depression (Belsher & Costello, 1988; Coyne, Pepper, & Flynn, 1999). Thus, the few studies that included interview-based diagnoses with representative populations have reported low rates of current, but higher rates of past, psychiatric morbidity (Maunsell, Brisson, & Deschenes, 1992; Silberfarb et al., 1980). These studies underscore the importance of assessing both current as well as past psychiatric morbidity, particularly because women with a past psychiatric history who do not have a current disorder may represent a subpopulation vulnerable to negative reactions to testing.

In summary, on an a priori basis, one might assume that anticipation of genetic testing for risk of breast cancer and receipt of results will entail risk of distress and psychiatric disorder. High-risk women suitable for testing may already have elevated distress and rates of psychiatric disorder that would interfere with education and informed consent. On the other hand, review of some relevant literatures raises the possibility that the risk may not be as great as anticipated. With the advent of more widespread testing,

the question of the psychological status of women seeking testing should not be left to conjecture (Botkin et al., 1996; Lerman, 1997). Knowledge of the rates of distress and psychiatric disorder is vital to ascertain the need for psychological screening, to design educational and counseling programs, to estimate the need for auxiliary mental health services, and to evaluate the incremental distress and morbidity occasioned by positive test findings.

The present study examined rates of psychological distress and psychiatric morbidity among a sample of women who were considered at high risk for breast and ovarian cancer on the basis of personal and family history. They had been enrolled in the registry of the Hereditary Breast and Ovarian Cancer Study conducted by the University of Michigan and then the University of Pennsylvania Cancer Center registry. Some of these women were deemed at high risk and were eligible for enrollment in the registry because they already had a diagnosis of breast cancer or ovarian cancer and had at least one other family member who had been diagnosed with one of these cancers. These women have a greater likelihood of contralateral breast cancer, ovarian cancer, or both than women without a family history. Other women in this study had not been diagnosed with breast or ovarian cancer themselves but were eligible for enrollment in the registry because they had at least two relatives who had been diagnosed with one of these forms of cancer.

The women were assessed at a time when they were anticipating the offering of genetic testing to them that could reveal whether they had an altered gene associated with increased risk of cancer. The Hereditary Breast and Ovarian Cancer Study was originally conceived primarily as basic research, not as a clinical service, but by the early 1990s, it became possible to perform linkage analyses with a few families so that it could be determined whether a particular member of the family had an increased risk of cancer. Experience disclosing the results of linkage analyses to some of these families highlighted the complex psychosocial issues involved in making such information available (Biesecker et al., 1993). Moreover, it was apparent at the time that a gene associated with increased risk of breast and ovarian cancer would soon be isolated, and more widespread testing would then become possible. A research project was initiated examining psychosocial issues associated with genetic testing in the Hereditary Breast and Ovarian Cancer Study sample of women. The data reported in this article are derived from baseline assessments obtained from these women in the year after the announcement that a strong candidate for the breast and ovarian cancer susceptibility gene, BRCA1, had been identified (Miki et al., 1994) and when the offering of genetic testing was widely expected to be imminent. Moreover, there was the anticipation that BRCA1 would account for more familial breast cancer than actually proved to be the case and that genetic testing would provide more information to these women than it has (Couch et al., 1997).

The first objective of this study was to assess general psychological distress, cancer worries, and current and past psychiatric disorder in women enrolled in a hereditary cancer registry. This is the first study using interview-based diagnoses to supplement self-report data in evaluating high-risk women. A second objective was to evaluate the concordance between self-report data and interview-based current and past psychiatric diagnoses. Self-report screening instruments are economical and readily administered but tend to have the disadvantage of low specificity as a means of

identifying psychiatric cases (Fechner-Bates, Coyne, & Schwenk, 1994). Moreover, the relationship between self-reported distress and depression is not fixed and constant across populations. For instance, a large-scale epidemiological study of adolescents found that the prevalence of elevated scores on the CES–D (Radloff, 1977) was so high (48%) and the prevalence of depression so low (2.5%) that there was little chance-corrected agreement between the CES–D and a diagnosis of depression (Roberts, Lewinsohn, & Seeley, 1991).

The inclusion of both self-report measures and diagnoses based on semi-structured interviews allowed us to examine the performance of the self-report measures for possible use as the first stage of a two-stage strategy for identifying psychiatric morbidity. Furthermore, this comparison allowed us to evaluate the conclusions about anxiety and depression in this population that are being made on the basis of self-report data (Lerman et al., 1996, 1998). The relationship between an elevated score on a measure of distress and a clinical diagnosis can be summarized in terms of the sensitivity and specificity of the self-report measure (Fletcher, Fletcher, & Wagner, 1988; Zarin & Earls, 1993). *Sensitivity* refers to the proportion of persons with a particular diagnosis who also score above a cutpoint on the self-report measure and who are, therefore, correctly identified as disordered by the measure. *Specificity* refers to the proportion of persons without a disorder who score below the cutpoint. For the purposes of evaluating the use of a self-report measure as a screening instrument, an additional summary statistic is informative: the positive predictive value. This value expresses the probability that a patient obtaining a positive screening score will have the disorder and depends on the prevalence of the disorder as well as the specificity and sensitivity of the test (Fletcher et al., 1988).

The substantial number of women in our sample who had a history of breast or ovarian cancer gave rise to a final, auxiliary aim of this research. These women were relatively long-term survivors of cancer. As we noted, much of what is known about adjustment and psychiatric morbidity of persons affected by cancer comes from samples biased toward elevated levels of distress and depressive and anxiety disorders. Our large sample allowed us to examine whether these past results hold for women who have not been recently diagnosed or who, as a group, are not typically in the midst of active treatment or the terminal stages of the disease.

Method

Sample and Recruitment Procedure

Women participating in the study were drawn from the registry of the Hereditary Breast and Ovarian Cancer Study conducted by the University of Michigan and the University of Pennsylvania Cancer Center. A heterogeneous set of criteria had been applied in the original recruitment of these women to the registry. Women previously diagnosed with breast or ovarian cancer were eligible if they had at least one other family member with one of these forms of cancer. In an effort to capture paternal transmission, some women were enrolled whose family members with breast or ovarian cancer were not first-degree relatives. Also, there was an oversampling of women from families with both breast and ovarian cancer. For women who had not been diagnosed with breast or ovarian cancer, the requirement was that they have two relatives with breast or ovarian cancer. In August 1995, women enrolled in the registry were sent a newsletter informing them of a study aimed at examining the psychological factors

associated with anticipating and receiving genetic testing. The newsletter gave them the opportunity to decline further solicitation concerning this study. Questionnaire packages and consent forms were then mailed to their homes. A cover letter was included explaining to participants that, on receipt of their questionnaires, a researcher would contact them to arrange a telephone interview. The letter emphasized that the information provided would be kept confidential. If a woman did not respond to this mailing by accepting or declining participation in the study, a follow-up letter was sent, and, if there was still no response, attempts were made to reach the woman by telephone. If women elected to pursue the next phase of the study, an appointment was arranged for a telephone interview. When participants were contacted by telephone, they again received an explanation of the voluntary nature of participation. On average, the questionnaires required 30 min to complete, and the telephone interviews lasted approximately 45 min. The interviews were conducted by well-trained interviewers with graduate training in clinical psychology, social work, or nursing. Of the 633 eligible women who were mailed questionnaires, 54 (9%) declined participation. For another 102 (16%) women, either available addresses and telephone numbers were no longer valid or no questionnaire was returned despite efforts to reach them by a follow-up letter and telephone calls. For reasons of confidentiality, we did not reveal the purpose of a telephone call when an answering machine or person other than the prospective respondent was reached. Our sense is that for the most part, this latter group had simply been lost to the registry, rather than representing passive refusals. Of the 477 women who returned a questionnaire, 464 received a telephone interview. The final sample consisted of 211 women with a previous history of breast or ovarian cancer, and 253 who did not have such a history.

Measures

Psychological distress. The 25-item version of the Hopkins Symptom Checklist (HSCL–25) was used to assess psychological distress. The scale uses 10 items from the HSCL–90 anxiety cluster, 13 items from the depression cluster, and 2 additional somatic symptoms (poor appetite; difficulty falling asleep or staying asleep). The same items also appear with inconsequential differences in wording on the Symptom Checklist 90 (Derogatis & Cleary, 1977). Hesbacher, Rickels, Downing, and Stepansky (1978) found that the HSCL–25 correlated highly with the standard 58-item version of the HSCL (Derogatis et al., 1974). The HSCL–25 has been widely used for the psychiatric screening of medical patients (Fink et al., 1995), and, with a cutoff of 44 for caseness, Hough et al. (1982) found that the HSCL–25 was comparable or superior to the CES–D (Radloff, 1977) in detecting psychiatric disorder, depending on the criterion used. There are extensive data using this scale with healthy, physically ill, and psychiatric samples where adequate rates of reliability have been reported (Cohen, Coyne, & Duvall, 1993; Coyne, Kessler, Tal, & Turnbull, 1987; Coyne & Smith, 1991; Cranford, Coyne, Sonnega, & Nicklas, 1998; Hesbacher, Rickels, Morris, Newman, & Rosenfeld, 1980; Pepper, Coyne, & Cohen, 1996). Consistent with past studies, coefficient alpha for the HSCL–25 was found to be .91.

Depression screening questions. Additional self-report screening questions for depression were taken directly from the questions assessing 2-week mood disturbance and associated impairment from the Structured Clinical Interview for *DSM–IV* (SCID; First, Spitzer, Williams, & Gibbon, 1995). One question inquired whether, in the past 6 months, there had been 2 weeks of depressed mood most of the day nearly every day. Another question inquired whether there had been 2 weeks of markedly diminished interest or pleasure in all, or almost all, activities. If the answer was affirmative to either of these questions, a follow-up question inquired whether there had been treatment or interference in role functioning. Rost, Burnam, and Smith (1993) previously reported sensitivity in excess of .80 and specificity in excess of .90 for the two questions with respect to a simultaneously obtained diagnosis of major depression using the Diagnostic Interview Schedule (DIS; Robins, Helzer, Croughan, & Ratliff, 1981).

Although these figures suggest some promise for these questions as a means of screening for depression, they may have been inflated by their direct correspondence to the questions in the DIS. Unlike the SCID used in the present study, the DIS is basically a lay-interviewer administered questionnaire and does not allow for interviewer probes of responses (Coyne, 1994).

Breast cancer worries. Two 5-point Likert-style items ranging from 1 (*not at all*) to 5 (*very much*) assessed how often women worry about developing breast cancer and the extent to which these worries interfere in their lives. These items have been used in a number of studies and have been found to be positively related to both general psychological distress and to cancer-screening adherence (Lerman et al., 1991; McCaul, Branstetter, O'Donnell, Jacobson, & Quinlan, 1998; Schwartz et al., 1995; Stefanek & Wilcox, 1991). These items were administered only to women without a history of breast or ovarian cancer.

Interview-based measures of psychiatric morbidity. Semi-structured interviews were conducted to assess current and past history of depression, anxiety, and alcohol use. Because of its modular construction, the SCID can be adapted for use in studies in which only a particular diagnosis is of interest (First et al., 1995). The mood disorders, anxiety, and alcohol use modules of the SCID were used in this study. The administration of the SCID was done by telephone because many of the participants were from out of state. Previous studies have shown the concordance of telephone-administered diagnostic interviews with face-to-face interviews for assessment of depression (Baer, Brown-Beasley, Sorce, & Henriques, 1993; Kendall, Neale, Kessler, Heath, & Eaves, 1992; Potts, Daniels, Burnham, & Wells, 1990; Wells, Burnam, Leake, & Robins, 1988). Also, Slutske et al. (1998) recently showed that the reliability and validity of alcoholism diagnoses and symptoms by telephone assessment is as good as what is obtained in face-to-face interviews. Concurrent with the present study, we conducted a reliability study comparing interviewers' diagnoses and ratings of diagnosis and depression symptoms with independent raters using 28 audiotapes of telephone assessments. There was 100% agreement for diagnosis and 97% agreement for specific symptoms.

Results

Basic Demographics

As can be seen in Table 1, there were no differences between women with and without a history of cancer for the demographic variables, except that women with a history were significantly older. As a whole, the women were in their late forties and were predominantly White (98%), Christian, married, and with an average of two children. One striking characteristic of this group was their high level of education and income. Most women had at least some college, worked outside the home, and had an annual family income that exceeded $54,000. These results are consistent with previous findings that women who seek genetic testing are generally well-educated and have a higher socioeconomic status (Codori, Hanson, & Brandt, 1994; Kash, Holland, Osborne, Miller, & Rosenthal, 1997). On average, 8.24 years had elapsed ($SD = 6.50$) since the women with a history of cancer were first diagnosed with cancer, indicating that these women were long-term survivors of cancer. Among those who had a history of breast or ovarian cancer, 50% reported unilateral mastectomy, 20% reported bilateral mastectomy, and 17% reported oophorectomy. Among those who did not have histories of breast cancer or ovarian cancer, 1% reported bilateral mastectomy, and 18% reported oophorectomy.

Table 1

Basic Demographic Characteristics of the Full Sample and Women With and Without a History of Cancer

Variable	All women (N = 464)			Women with a history of cancer (n = 211)			Women without a history of cancer (n = 253)		
	M	SD	%	M	SD	%	M	SD	%
Age (in years)	49.0	12.2		51.9ₐ	11.0		46.2ₐ	13.3	
Religion									
Christian			74			70			79
Marital status									
Married or with a partner			83			84			83
No. of children	2.0	1.8		2.0	2.0		2.0	1.7	
Education									
At least some college			80			76			81
Employed outside home			61			57			63
Income	$54,500			$54,000			$54,500		

Note. Means with the same subscript differ at $p < .01$.

Psychological Distress

Table 2 presents findings concerned with self-reported psychological distress for the full sample as well as for women with and without histories of cancer. As can be seen, there were no differences between the two groups on the HSCL-25, and both groups had a mean score below the clinical cutpoint of 44. Overall, only 23% (confidence interval [CI] 19%–27%) of the women scored in the clinically distressed range. By way of comparison, these women were similar or lower than primary medical care samples (Fechner-Bates et al., 1994; Hesbacher et al., 1980) and nearly identical to women recruited for a recent clinical trial at other sites comparing alternative models of pretest education for BRCA1 testing (Audrain et al., 1997). However, the women in the present study were substantially lower in distress than wives of post-myocardial infarction patients (Coyne & Smith, 1991), persons living with a depressed person (Coyne et al., 1987), female congestive heart failure patients and wives of congestive heart failure patients (Cranford et al., 1998), and divorced women who do not have custody of their children (Santora & Hays, 1998).

Breast Cancer Worries

Women who had never been diagnosed with cancer scored 2.88 (*SD* = 0.98) on the measure of breast cancer worries and 1.65

Table 2

Psychological Distress as Measured by the Hopkins Symptom Checklist, 25-Item Version (HSCL-25)

Psychological distress	All women (N = 464)	Women with a history of cancer (n = 211)	Women without a history of cancer (n = 253)
HSCL-25			
M	37.5	37.7	37.5
SD	9.2	9.2	9.2
% in clinical range (greater than 43)	23	22	24

(*SD* = 0.93) on the measure of how much these worries interfered with their lives. Although only 8% of the women endorsed the lowest rating (i.e., *not at all*) of how often they worried about developing breast cancer, most (59%) of the women reported that worries about cancer interfered with their daily lives "not at all." Worries and interference were correlated with each other ($r = .47$, $p < .001$) and with general psychological distress ($r = .31$, $p < .001$, and $r = .30$, $p < .001$, respectively).

Psychiatric Disorder

Table 3 presents findings from interview-based measures of current and lifetime psychiatric morbidity, including depression, anxiety, and alcohol abuse. In the overall sample, only five women (1%; CI 0.1% to 2.0%) met criteria for current major depressive disorder, four of whom had histories of cancer. These figures can be interpreted in light of a reported one-year prevalence of major depressive disorder among primary medical care patients ranging from 5% to 14% (Coyne, Fechner-Bates, & Schwenk, 1994; Katon & Schulberg, 1992) and a one-month prevalence of 3% in community samples of women (Regier et al., 1988). Eighty-seven women (18.75%; CI 15%–22%) were found to have a lifetime history of major depressive disorder, 46 of whom (53%) had a history of breast or ovarian cancer. This rate can be compared to a lifetime prevalence of major depression in women of 8% in the Epidemiologic Catchment Area Study (Weissman et al., 1993) and 21% found in the National Co-Morbidity Study (Kessler et al., 1994). Thus, the lifetime prevalence of major depressive disorder for these high-risk women was low and in the range that would be expected for a sample of community-residing women of this age. One woman with a history of cancer and one without this history met criteria for dysthymic disorder. One woman with a history of cancer and two without this history met criteria for generalized anxiety disorder. Three women without a history of cancer met criteria for mixed anxiety and depressive disorder. Only one woman was found to have an alcohol abuse problem, and she did not have a history of cancer.

Table 3
Psychiatric Morbidity as Assessed by the SCID

Psychiatric diagnosis	All women (N = 464)		Women with a history of cancer (n = 211)		Women without a history of cancer (n = 253)	
	No.	%	No.	%	No.	%
Current major depression	5	1.0	4	1.9	1	0.4
Lifetime major depression	87	18.8	46	21.8	41	16.2
Current major depression (mood disorder GMC)	2	0.4	2	1.0	0	0.0
Lifetime major depression (mood disorder GMC)	10	2.0	7	3.3	3	1.2
Generalized anxiety disorder	3	0.6	1	0.5	2	0.8
Mixed anxiety depression	3	0.6	0	0.0	3	1.2
Dysthymia	2	0.4	1	0.5	1	0.4
Alcohol use (current)	1	0.2	0	0.0	1	0.4

Note. SCID = Structured Clinical Interview for DSM–IV; mood disorder GMC = mood disorder due to a general medical condition.

Performance of Screening Instruments

Such a low prevalence of current major depression precludes screening instruments from being efficient in identifying cases. A score meeting or exceeding the clinical cutpoint of 44 on the HSCL–25 yielded a sensitivity of 80%, a specificity of 80%, and a positive predictive value of 4% for depression. The respective values for the HSCL–25 with generalized anxiety as the criterion were 100%, 79%, and 3%. The respective values for the HSCL–25 with either depression or generalized anxiety as the criterion were 88%, 93%, and 7%. Women's self-report on a 2-weeks mood disturbance screening question yielded a sensitivity of 60%, a specificity of 86%, and a positive predictive value of 5% for major depression. Little difference was found for including the requirement of a report of impairment for the 2-weeks mood disturbance in the form of seeking treatment or experiencing difficulties in interpersonal functioning. Overall, screening for psychiatric morbidity using a standard self-report measure would be a highly inefficient process in which most women would not screen positive, and the vast majority of those who screened positive would prove to be false positives in terms of psychiatric diagnosis.

Discussion

The high-risk women in this sample were remarkably free of psychological distress and psychiatric morbidity. These results held for women both with and without histories of cancer. Only the women without histories of cancer were assessed for cancer worries, but these women were found to have little or no interference of cancer worries with their daily lives. Despite their increased risk for breast and ovarian cancer, as well as their repeated exposure to cancer either in themselves or their relatives, these women compared well with women drawn from other samples. They were comparable to and—depending on the comparison sample—had even lower rates of psychological distress and psychiatric disorder than women drawn from primary medical care and community settings. Thus, it appears that these women have no excess of psychological distress that may be attributed to their high risk

status. As they approached the process of counseling, education, and decision making about testing, they were thus not, as a group, impaired by their psychological state.

Our second objective was to examine the performance of self-report measures for the purposes of screening for clinical disorder. There is an absence of past data concerning the relations between distress and psychiatric morbidity among such high-risk women. We found that a low score on a standardized measure of distress was a good indicator that the women were not suffering from major depression or from an anxiety disorder. Yet women scoring above a standard cutpoint were unlikely to meet criteria for a clinical disorder, indicating that the measure had exceptionally low positive predictive value. The positive predictive value of 4% for major depression in the present study is still a fraction of the 15%–30% obtained in primary care populations (Fechner-Bates et al., 1994; Hough et al., 1982). Indeed, a woman screening positive for depression on the self-report measure in the present sample would be no more likely to be depressed than a randomly selected, unscreened woman in the general medical population (Coyne et al., 1994; Katon & Schulberg, 1992). The performance of these instruments in detecting disorder in this study was constrained by the low prevalence of disorder (Elwood, 1993), and it is unlikely that any modifications of the screening instrument would result in substantially improved performance. From a practical standpoint, these results demonstrate that, as a group, the women do not require extensive psychological screening and diagnostic assessment. The routine use of screening instruments would be inefficient in that less than 10% of the women who were distressed would meet criteria for a clinical disorder.

One interpretation of these findings is that women in our sample who screened positive for psychological distress were nonetheless no more likely to be clinically depressed than an unscreened woman in a primary care setting. What are the relevant differences between clinical depression and psychological distress? A diagnosis of depression suggests the likelihood of a debilitating, but readily treatable condition but also one with a high rate of recurrence (Depression Guideline Panel, 1993). Psychological distress

when a clinical disorder has been ruled out is more ambiguous in its implications, and, on a population basis, much of it proves self-limiting and not in need of psychological or pharmacological treatment.

The results obtained in this study have implications for the interpretation of other studies of the adjustment of high-risk woman who are anticipating, or who have received, results of genetic testing. Such studies use self-report measures of distress as indices of anxiety and depression, yet elevated scores on such instruments may be even less indicative of psychiatric disorder than has been previously assumed. It is important that claims of clinically significant distress be grounded in comparisons to normative data and that they be backed by evidence that such distress actually reflects impairment or psychiatric morbidity. Thus, a recent article examined persons who are members of families with known mutations of BRCA1 or BRCA2 but who themselves declined testing (Lerman et al., 1998). Concern was expressed that 18% had elevated distress. Yet this rate is lower than a primary medical care sample and is even lower than the baseline assessment of the women in the present sample. Moreover, preliminary findings concerning psychological consequences of genetic testing for risk of breast cancer suggest that there are little enduring effects on levels of psychological distress (Croyle, Smith, Botkin, Baty, & Nash, 1997; Lerman et al., 1996). These results are at variance with what might have been predicted from case reports about offering testing to high-risk families (Biesecker et al., 1993; Dudok deWit et al., 1997; Lynch et al., 1997), but they are consistent with other empirical findings concerning HD (Codori, Slavney, Young, Miglioretti, & Brandt, 1997; Tibben, Roos, & Niermeijer, 1997; Wiggins et al., 1992).

It is premature to come to any final conclusions concerning the adjustment of high-risk women anticipating and receiving genetic testing for risk of breast and ovarian cancer. However, it is also important that emerging data not be dismissed or distorted simply because they contradict preconceived notions. Unfortunately, such dismissal or distortion has sometimes been the case in the literature concerning genetic testing. In genetic screening for both HD and mutations of BRCA1, findings that recipients of positive test results do not experience substantial distress have been minimized and distorted (Lawson et al., 1997; Taylor & Myers, 1997) and even dismissed with arguments "that low scores on 'mental health scales' can reflect opposite conditions. Low scores usually indicate good psychological health; on the other hand, distress may be present, but denied in order to maintain an illusion of mental health" (Dudok deWit et al., 1997, p. 387; see also Dudok deWit et al., 1998). Results obtained in larger scale studies of high-risk persons with standardized self-report and semi-structured diagnostic interviews are to be preferred to results of studies using unvalidated measures and to clinical speculations concerning potentially unrepresentative cases. For instance, the genetic testing literature continues to contain considerable speculation about the risk of so-called survivor's guilt among persons who are not found to have gene mutations associated with heightened risk of disease (Dudok deWit et al., 1998; Huggins et al., 1992; Tibben et al., 1997). This speculation occurs despite the fact that no empirical study has ever yielded evidence that being informed that one does not have a mutation increases distress. Finally, interpretation of empirical data should be informed by relevant norms for measures, known correlates, and base rates of phenomena in relevant populations. In the present study, high-risk women were found to be relatively free of psychological distress, and elevated psychological distress was associated with a rate of syndromal depressive and anxiety disorders less than the prevalence of these disorders in unscreened general medical populations. This latter finding suggests the need to temper claims about anxiety and depression associated with testing that are made solely on the basis of self-report measures. Moderately elevated distress scores may simply reflect the norms for relevant comparison populations—a possibility needing more attention in studies lacking a comparison group—and endorsement of items indicating worries about disease may indicate understandable concern about their risk status rather than psychiatric symptoms, morbidity, or impairment.

High-risk women recruited to a hereditary breast and ovarian registry for the purposes of research undoubtedly represent a socially advantaged group, and demographic information from the sample bore this out. Additional data from this sample have given further indication of the social resources of this group of women (Coyne & Anderson, 1999). The married women had stable and highly satisfying marriages, and their husbands were supportive and involved in decision making about managing the women's risk status, including genetic testing. Unmarried women in the sample had similarly low levels of distress, and both married and unmarried women had mobilized considerable support from female relatives. These findings give rise to an important caveat about generalizations from women seeking genetic testing in the context of hereditary cancer registries and research protocols to the larger pool of high-risk women in the community. It is possible that women who seek genetic testing in noncommunity medical settings outside of research protocols may differ. Some women may seek genetic testing in the community because they are distressed by a recent medical finding such as an ambiguous lump in the breast or an abnormal pap smear or by a recent death or diagnosis of cancer in a relative. There is evidence that many women with family histories of cancer have not had extensive discussion of the personal implications of this history (Stefanek & Wilcox, 1991). Such women may be particularly ill-prepared for education and decision making concerning genetic testing. Studies of such women seeking testing under those circumstances are sorely needed. We should not accept uncritically the broad generalizability of results of psychological studies of self-selected registry samples in the absence of comparative data.

Requiring that high-risk women seeking predictive testing for risk of breast and ovarian cancer undergo psychological assessment and counseling increases the cost of genetic testing and needs to be justified by data. Moreover, there have recently been null findings concerning the effects of a program offering monthly monitoring of psychological distress and psychosocial intervention for distressed women who have received a diagnosis of breast cancer (Maunsell, Brisson, Deschenes, & Frasure-Smith, 1996). A similar program resulted in negative outcomes for women recovering from myocardial infarction, and the authors suggested that repeated focusing on the women's relatively minor psychological distress may have disrupted their normal coping efforts (Frasure-Smith et al., 1997). These findings are relevant in suggesting that services offered to manage the distress of high-risk women seeking predictive testing for breast cancer must be tailored to their actual, rather than presumed, needs. Given that high-risk women are no more distressed than women in relevant comparison populations, it

may not be reasonable to assume that interventions targeting distress presumed to be associated with high risk status will, on a population basis, bring about a significant reduction in distress. Of course, if an individual woman expresses a need for such services, she should be offered them, but the present data cast doubt that there will be a high need or interest in such services, and this fits with our clinical experience.

One aim of the present study was to establish baseline differences in the adjustment of high-risk women who had histories of cancer versus those who did not. The goal was to provide a means of understanding any changes in the subsequent adjustment of women without histories of cancer who test positive. However, we instead found that the women with histories of cancer were similarly low in distress and psychiatric disorder and that there were no differences between women with and without this history. Indeed, we have produced evidence of good psychological adjustment for long-term survivors of breast cancer with what is perhaps one of the largest samples to receive assessment by psychiatric interview. These results are consistent with past speculations concerning the ability of patients to make a positive long-term adjustment to cancer when they are neither receiving active treatment nor facing the terminal stages of the disease (Massie & Holland, 1990).

Overall, we set out in the larger project from which these data were drawn to examine what was presumed to be the psychological vulnerability of women anticipating genetic testing. What we have ended up demonstrating is the remarkable psychological intactness of these women. Attention can be profitably turned to better understanding why these women defy the not unreasonable assumption that they would be a distressed, depressed, and anxious group. The experience of living with familial risk of cancer may well have organized psychological resources and fostered resiliency that more than compensate for any vulnerability associated with it. Adversity can produce resiliency as well as vulnerability (Schaefer & Moos, 1992; Caspi & Moffitt, 1991), and high-risk women anticipating testing may provide an excellent opportunity to study this.

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Marital Status, Marital Satisfaction, and Support Processes Among Women at High Risk for Breast Cancer

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This study explored marital status, social support processes, and psychological distress among women at high risk for breast and ovarian cancer who were anticipating genetic testing. In addition to substantive findings, it presents a means of using nonsense coding (J. Cohen & P. Cohen, 1983) to include unmarried persons in regression analyses examining the importance of marital support. These women had mobilized high levels of social support. Married and unmarried women did not differ in distress, but women had to have more satisfying marriages than average to be equivalent to unmarried women. For the married women, husbands were more involved and more influential in decision making than female relatives, even in distressed marriages. Negativity from close relationships, particularly the spouse, had more influence on these women's well-being than did positive involvement. The authors' findings suggest that counseling and education programs need to accommodate the key role that husbands have in decision making concerning genetic testing for risk of breast cancer.

Social support from husbands and close family members has been identified as a key resource in women's adjustment to breast cancer diagnosis and treatment (Bloom, 1996; Lichtman, Taylor, & Wood, 1987; Manne, 1998; Peters-Golden, 1982; Pistrang & Barker, 1995). By extension, such social support should be an important determinant of women's ability to adjust to an awareness that they are at high risk for cancer. Women's knowledge that they are

members of a high-risk family involves a recognition that they are personally at a heightened risk for cancer, that they may need to make decisions as to how to manage this risk under conditions of considerable ambiguity, and that they may have transmitted this risk to their children.

The present study explored marital status and social support processes in relation to psychological distress among women who were considered at high risk for breast and ovarian cancer on the basis of personal and family history. Some of these women were deemed at high risk because they already had a diagnosis of breast cancer or ovarian cancer and had at least one other family member who had been diagnosed with one of these cancers. These women have a greater likelihood of contralateral breast cancer and ovarian cancer than women without a family history. Other women in this study had not been diagnosed with breast or ovarian cancer themselves but had at least two relatives who had been diagnosed with one of these forms of cancer. All of the women in this study had previously been enrolled in the registry of the Hereditary Breast and Ovarian Cancer Study conducted by the University of Michigan and,

later, the University of Pennsylvania Cancer Center. They were assessed for social support and psychological distress at an important time: while they were anticipating the offering of genetic testing, which could reveal whether they had an altered gene associated with an increased risk of cancer. The Hereditary Breast and Ovarian Cancer Study was originally conceived primarily as basic research, not as a clinical project. However, it became possible by the early 1990s to perform linkage analyses so that for a few families it could be determined whether a particular member of the family had an increased risk of cancer. Experience disclosing the results of linkage analyses to some of these families highlighted the complex psychosocial issues involved in making such information available (Biesicker et al., 1993). Moreover, it was apparent, at the time, that a gene associated with increased risk of cancer would soon be isolated, and more widespread testing would then become possible. A research project was initiated examining psychosocial issues associated with genetic testing in the Hereditary Breast and Ovarian Cancer Study sample of women, and the data reported in this article are derived from baseline assessments. These data were collected in late 1995 and early 1996, starting the year after the announcement that a strong candidate for the breast and ovarian cancer susceptibility gene BRCA1 had been identified (Miki et al., 1994) and a time when the offering of genetic testing was widely expected to be imminent. Furthermore, there was the anticipation that BRCA1 would account for more familial breast cancer than actually proved to be the case, and that genetic testing would provide more information to these women than it has (Couch et al., 1997).

There had been concerns that positive findings would carry the threat of psychological and psychiatric morbidity for the women and their family members, disruption of family relationships, and impairment of the women's surveillance and adherence behaviors. There were also concerns that, among the high-risk women seeking testing, an existing level of distress or vulnerability to major depression might impair their ability to become educated, make an informed choice about testing, and use their test results to manage their risk of cancer. However, initial findings indicate that the high-risk women anticipating genetic testing are remarkably free

of psychological distress and clinical depression and anxiety disorders (Coyne, Benazon, Gaba, Calzone, & Weber, in press). They have less distress and psychiatric morbidity than women drawn from the waiting rooms of primary care physicians (Coyne, Fechner-Bates, & Schwenk, 1994; Fechner-Bates, Coyne, & Schwenk, 1994). Moreover, results revealing that women have an altered gene associated with heightened risk of cancer produced only mild and temporary elevations in distress (Lerman et al., 1996). Given findings concerning the relative lack of distress and depression among these women, what was designed as a study of their vulnerability needs to be reconceptualized as a study of their robustness and resiliency.

Questions remain about the representativeness of women drawn from hereditary breast cancer registries, and, therefore, the generalizability of results of studies of the psychological effects of genetic testing conducted with them. These registry women are self-selected and socially advantaged in terms of education and income (Coyne et al., in press). Members of high-risk families jointly participate in these registries, and, in the process of accumulating family history data, they typically have marshalled considerable social support to manage their shared sense of being at high risk for cancer. In contrast, women from the community seeking testing are likely to be less socially advantaged. They are also likely to be less involved in discussions with family members about their risk of cancer, less informed about genetic testing, and less psychologically prepared for the dilemma of whether personally to proceed with testing. Social support related to being at high risk and to the decision about testing may be deficient or absent. Important in itself, an understanding of support processes among the high-risk registry women may also prove useful in defining how they differ from women in the community seeking testing and in the design of compensatory services for the women from the community.

Because a considerable proportion of the women in our sample had already been diagnosed with breast cancer, we were able to compare them with women who were high risk but without a personal history of cancer. Most of the women were married, but there were sufficient numbers of unmarried women to examine some differences in support processes

between married and unmarried high-risk women. There has been a long-standing interest in the role of marriage in the well-being of women, but the bulk of research has focused on comparisons between married women and men rather than on differences between married and unmarried women (Kessler & McRae, 1984). However, married women have been found to be less distressed than unmarried women in some community studies (Kessler & McRae, 1984; Williams, 1988; see Wood, Rhodes, & Whelan, 1989, for a review) and rated themselves as happier (Stack & Eshleman, 1998). Furthermore, spouses are generally the most important sources of support for married persons (Brown & Harris, 1978; Coyne & DeLongis, 1986). There is some limited evidence that women in strained marriages may actually be worse off than unmarried women (Aneshensel, 1986; Cutrona, 1996; Weissman, 1987), and that support from other sources will not compensate for what is lacking in the marriage (Brown & Harris, 1978; Coyne & DeLongis, 1986). Yet the women in our study are members of high-risk families, with first-degree female relatives in similar predicaments. The support and information that close female relatives provide, the manner in which these relatives cope with their own dilemma, and the decisions they make about testing are likely to have profound effects on the high-risk women. It may be that, as a result of the mobilization of social support around the shared risk of cancer, female relatives have more, and spouses correspondingly less, influence on the level of psychological distress of these women.

Finally, involvement in close relationships can be a liability as well as an asset in coping with chronic illness (Cutrona, 1996; Fiske, Coyne, & Smith, 1991; Lyons, Sullivan, Ritvo, & Coyne, 1995). Husbands of cancer patients are often fallible as sources of support, even if they are important determinants of the women's well-being. Women may find exchanges with their husbands less helpful than with female relatives who are similarly at risk for cancer, and husbands' avoidance of open discussion about risk could be problematic (Pistrang, Barker, & Rutter, 1997). So it becomes important to examine negative as well as positive aspects of involvement in social relationships. Here, too, the mobilization of support among female relatives may decrease the importance of the marital relationship.

An understanding of the psychosocial resources of high-risk registry women anticipating genetic testing has practical implications. Moreover, the opportunity to study this large sample of women at this key point in time also allowed us to explore some more general theoretical issues: social support processes among married and unmarried women; robustness of findings concerning marriage as the key source of support for married women; and relations between perceived support and specific support processes to compare the importance of husbands' and female family members' opinions in the women's decision-making processes about genetic testing and risk reduction behaviors.

Method

Sample and Recruitment Procedure

Women participating in the study were drawn from the registry of the Hereditary Breast and Ovarian Cancer Study conducted first by the University of Michigan and subsequently by the University of Pennsylvania Cancer Center. To be included in the registry, women who had no personal history of breast or ovarian cancer had to have at least two cases of either cancer in their family, and women with a personal history of breast or ovarian cancer had to have at least one other family member with such a history.

In August 1995, women who had previously been enrolled in the registry were sent a newsletter informing them of a study aimed at examining the psychological factors associated with anticipating and receiving genetic testing for risk of breast and ovarian cancer. The newsletter gave them the opportunity to decline further solicitation concerning this study. Questionnaire packages and consent forms were then mailed to the homes of the women who did not decline further solicitation. A cover letter was included explaining to participants that, on receipt of their questionnaires, a researcher would contact them to arrange a telephone interview. The letter emphasized that the information provided would be kept confidential. When participants were contacted by telephone, they were again provided with an explanation of the voluntary nature of participation. A follow-up letter was sent and a query made by telephone if women did not respond to the mailing by returning the questionnaire or declined participation in the study. An appointment was arranged for a telephone interview if women elected to pursue the next phase of the study when contacted by telephone after returning their questionnaire. On average, the

questionnaires required 30 min to complete, and the telephone interviews lasted approximately 45 min. All interviewers were trained and had graduate training in clinical psychology, social work, or nursing.

Of the 633 eligible women who were sent questionnaires, 477 (75%) returned them. Of the 156 women who did not return questionnaires, 54 declined participation and 102 did not return a questionnaire despite efforts to reach them by follow-up letter and telephone call. Our sense is that, for the most part, this latter group had simply been lost to the registry rather than representing passive refusals. Of the 477 women who returned a questionnaire, 464 received a telephone interview. The final sample consisted of 211 women with a history of breast or ovarian cancer and 253 without such a history. Of these 464 women, 394 were married ($n = 380$) or living with a partner ($n = 14$). For the purpose of the analyses presented here, the unmarried women living with a partner were included in the married group, leaving 56 women in the unmarried group.

Key Measures

Cancer status and time since diagnosis. Registry records of the women's personal history of cancer were verified by self-report on the questionnaire. For women with a history of cancer, another item on the questionnaire inquired about the date of first diagnosis of breast or ovarian cancer. The difference between that date and the date on which the questionnaire was completed served as the length of time since diagnosis for the women with a history of cancer.

Perceived social support from spouses and female relatives. Questions derived from the Inventory of Socially Supportive Behaviors (Barrera, Sandler, & Ramsay, 1981) were used to assess women's perceptions of supportive behaviors from their spouse and the high-risk female relative to whom they were closest. Women responded yes or no to 13 items assessing the extent to which both their spouse and female family member exhibited emotionally supportive behaviors such as offering comfort and reassurance and active listening (e.g., "listened to you talk about your private feelings"). They similarly responded to 7 items regarding unsupportive behaviors from their spouse and female relative (e.g., "minimized your worries or concerns" and "let you down when you were counting on him/her"). These items were based on past surveys of cancer patients concerning unhelpful and unsupportive behaviors they received (Herbert & Dunkel-Schetter, 1992; Gurowka & Lightman, 1995). Coefficient αs were as follows: supportive behavior from the spouse and closest at-risk female family member, .77 and .81,

respectively; unsupportive behavior from the spouse and closest female relative, .69 and .77, respectively.

Cancer-specific social support processes. As part of the telephone interview, women were asked several questions scored on 4-point Likert scales (1 = *not at all*, 2 = *a little*, 3 = *somewhat*, 4 = *a great deal*) to assess their perceptions of how supportive their spouse and a sister have been surrounding their cancer or being at high risk for cancer. Note that, whereas the perceived support questions described previously focused on the closest female relative, these questions inquired about a sister. By referring specifically to a sister, the intent was to focus on a female relative who was at equivalent risk of being a carrier of a gene mutation but not on a relative, such as mother or daughter, for whom there might be issues of guilt and responsibility over transmission of the gene. These items addressed the frequency of discussions about cancer and genetic risk, women's satisfaction with these discussions, and the importance of the opinions of their spouse and sister in the decisions the women make about reducing their cancer risk and undergoing genetic testing.

Psychological distress. The 25-item version of the Hopkins Symptom Checklist (HSCL-25; Hough, Landsuerk, Stone, & Jacobson, 1982) was used to assess psychological distress. It consists of the anxiety and depression items and two somatic items from the standard 58-item version (Derogatis, Lipman, Rickels, Uhlenuth, & Covi, 1974). The same items also appear with inconsequential differences in wording on the Symptom Checklist 90 (Derogatis & Cleary, 1977). Hesbacher, Rickels, Downing, and Stepansky (1978) found that the HSCL-25 correlated highly with the standard 58-item version Hopkins Symptom Checklist (Derogatis et al., 1974). Using a cutoff of 43 for caseness, Hough et al. (1982) found that the HSCL-25 was comparable or superior to the Center for Epidemiological Studies Depression Scale (Radloff, 1977) in detecting psychiatric disorder, depending on the criterion used. There are extensive data using this scale with healthy, physically ill, and psychiatric samples for which adequate rates of reliability have been reported (Cohen, Coyne, & Duvall, 1993; Coyne & Smith, 1991; Cranford, Coyne, Sonnega, & Nicklas, 1998; Hesbacher, Rickels, Morris, Newman, & Rosenfeld, 1980; Pepper, Coyne, & Cohen, 1996). Consistent with past studies, coefficient α for the HSCL-25 was found to be .91, indicating that general psychological distress is being assessed (Cyr, McKenna-Foley, & Peacock, 1985; Tennen, Affleck, & Herzberger, 1985).

Marital adjustment. Marital adjustment was assessed using the Dyadic Adjustment Scale (DAS; Spanier, 1976). It is probably the most validated of such measures, having been used in more than 1,000 studies (Spanier, 1988). Factor analyses finding a single factor indicative of general marital satisfaction (Kazak, Jarmas, & Snitzer, 1988; Sharpley & Cross,

1982) suggest the use of a summary score rather than the four subscales that were originally proposed (Spanier, 1976).

Results

Demographic Characteristics

As a group, the women were predominantly White (98.1%), primarily Christian (74.2%), of middle age ($M = 48.52$ years, $SD = 12.07$ years), well educated (61.0% had at least completed college), and well-off financially (65.5% had a household income of at least $40,000). Most were married (84.9%), and they tended to have stable marriages, as judged by the fact that 81% had been married only once.

Table 1 presents demographic variables for the women, classified by history of cancer and whether they were currently married or unmarried. In terms of significant differences, women with a history of cancer were significantly older than those without such a history, $F(1, 440) = 25.47$, $p < .001$, and currently married women were significantly older than the currently unmarried women, $F(1, 440) = 24.76$, $p < .001$. Also significantly more of the women with a history of cancer were Christian, $\chi^2(1, N = 462) = 4.95$, $p < .05$. As might be expected, women who were married reported a higher household income than those who were not, $F(1, 435) = 87.16$, $p < .001$.

Bivariate Pearson Correlations of Distress and Support Variables

Table 2 displays correlational analyses for the married women. As can be seen, the correlations were very similar for women with and without a history of cancer. Women's level of psychological distress was related to a lack of support from both their spouse and closest female family member at high risk for cancer. It is notable that there were also significant correlations between perceived support from female family members and support from spouses and between unsupportive behaviors from relatives and unsupportive behaviors from spouses.

When the relevant correlations were examined for unmarried women, only one was significant. For women without a history of cancer, perceiving their female family members as supportive was negatively correlated with perceiving their female family members as unsupportive ($r = -.38$).

Differences in Psychological Distress and Perceived Support as Related to Cancer Status, Marital Status, and Marital Satisfaction

Three 2 (cancer history: yes, no) $\times$ 3 (marital status-satisfaction: not married, married dissatisfied, married satisfied) analyses of variance (ANOVAs) were conducted to examine differ-

Table 1
Demographic Characteristics by Breast Cancer and Marital Status

Variable	History of cancer		No history of cancer	
	Married ($n = 182$)	Not married ($n = 32$)	Married ($n = 212$)	Not married ($n = 47$)
Mean age (years) (SD)[a]	50.09 (10.56)	60.32 (12.41)	45.27 (10.70)	49.99 (16.38)
White race (%)	98.9	96.9	97.6	97.9
Christian religion[b] (%)	68.3	83.9	80.2	76.6
Completed some college (%)	81.9	67.7	81.6	83.0
Employed outside home (%)	62.6	53.3	65.4	61.7
Mean household income[c]	$53,600	$25,000	$53,900	$33,900
First marriage (%)	81.7	NA	81.3	NA
Ovarian cancer diagnosis (%)	3.4	10.0	NA	NA
Mean years since breast cancer diagnosis (SD)	7.55 (5.79)	12.54 (8.79)	NA	NA
Remission (%)	89.9	92.6	NA	NA

Note. NA = not applicable.
[a]Significant effect for history of cancer ($p < .001$) and marital status ($p < .001$). [b]Significant effect for history of cancer ($p < .05$). [c]Significant effect for marital status ($p < .001$).

Table 2
*Bivariate Pearson Correlations of Age, Distress, and Support Variables
for Married Women*

Variable	1	2	3	4	5	6
1. Age	1.00	−.14	−.12	.00	−.16	.03
2. HSCL-25	.01	1.00	−.22**	.30***	−.22**	.14
3. Spouse support	−.17*	−.08	1.00	−.51***	.36***	−.14
4. Spouse unsupportive	.05	.25***	−.53***	1.00	.00	.21*
5. Female relative support	.10	−.16*	.21**	−.06	1.00	−.35***
6. Female relative unsupportive	−.09	.13	−.02	.21**	−.54***	1.00

Note. Correlations for women with a history cancer are above the diagonal and
those for women without such a history are below the diagonal. HSCL-25 =
Hopkins Symptom Checklist (25 variables).
*$p < .05$.   **$p < .01$.   ***$p < .001$.

ences in distress and social support from female family members. The cutpoint of 107 on the DAS was used to classify women as being in a maritally dissatisfied relationship (Crane, Allgood, Larson, & Griffin, 1990). Sixty-seven percent of the women scored above the 107 cutpoint, thus indicating that they were in a satisfying marital relationship, with no differences between the groups with respect to history of cancer. For psychological distress, there was a main effect for marital status/satisfaction, $F(2, 440) = 20.06, p < .001$, but no significant main effect for history of cancer, $F(1, 440) = 0.18, p = .67$, or interaction, $F(2, 440) = 0.67, p = .51$. A Tukey honestly significant differences post hoc test revealed that maritally dissatisfied women reported significantly more psychological distress than both unmarried women and satisfactorily married women. However, as can be seen in Table 3, the mean distress score for

maritally dissatisfied women was still below the clinical cutpoint on the HSCL-25 of 43. For support from female family members, there was only a significant effect for marital status/satisfaction, $F(2, 395) = 3.06, p < .05$, but no main effect for history of cancer, $F(1, 395) = 2.72, p = .10$, or interaction effect, $F(2, 395) = 0.67, p = .51$. Again, a Tukey honestly significant differences post hoc test revealed that married women who were satisfied with their marriages reported significantly more support from female family members than did unmarried women. The amount of support from female relatives reported by maritally dissatisfied women did not differ from that reported by both unmarried women and women in a satisfying relationship (see Table 3). In terms of unsupportive behaviors from female family members, there was no main effect for martial status/ satisfaction, $F(2, 389) = 1.39, p = .25$, but

Table 3
Effects of Marital Status/Satisfaction on Distress and Social Support

Variable	Not married (n = 70)		Distressed marriage (n = 124)		Satisfactory marriage (n = 248)		df	F
	M	SD	M	SD	M	SD		
HSCL-25	37.10a	9.59	41.95b	10.35	35.79a	7.64	2, 445	20.06***
Female relative support	7.59a	3.92	7.85ab	2.95	8.54b	3.03	2, 400	3.06*
Female relative unsupportive	0.21a	0.64	0.28a	0.71	0.16a	0.56	2, 394	1.39
Spouse support	NA		7.53	2.93a	9.84	1.73b	1, 356	91.01***
Spouse unsupportive	NA		0.79	1.03a	0.13	0.42b	1, 345	70.92***

Note. Row means sharing a common subscript are not significantly different. HSCL-25 = Hopkins Symptom
Checklist (25 variables); NA = not applicable.
*$p < .05$.   ***$p < .001$.

women without a history of cancer reported receiving significantly more unsupportive behavior, $F(1, 389) = 4.62, p < .05$. The interaction was not significant, $F(2, 389) = 0.33, p = .72$.

To examine support that married women perceived from spouses, two similar 2 (history of cancer) $\times$ 2 (married dissatisfied, married satisfied) ANOVAs were conducted. Referring to Table 3, women who were not in a distressed relationship perceived significantly more support from their husbands than those in a distressed relationship, $F(1, 353) = 91.01, p < .001$. In addition, women without a history of cancer reported more spousal support than those with a history, $F(1, 353) = 13.64, p < .001$. The interaction effect was not significant, $F(1, 353) = 0.60, p < .40$. As would be expected, women in a distressed relationship perceived more unsupportive behaviors from their spouses than did women who were not in a dissatisfied relationship, $F(1, 342) = 70.92, p < .001$. There was not a significant main effect for history of cancer, $F(1, 342) = 1.05, p = .31$, or an interaction effect, $F(1, 342) = 0.58, p = .45$.

An interesting question that is seldom answered in the empirical literature concerns the level of marital satisfaction required to render married women equivalent to unmarried women in psychological distress. This question can readily be addressed in the following fashion. First, a regression equation is constructed predicting psychological distress (y) among married women from their level of marital satisfaction, as measured by the DAS (x). Then the mean level of psychological distress for unmarried women is substituted for y, and the equation is solved to obtain the value for x needed to obtain y. Thus, among the married women $y = a + bx$ yields $y = 60.06 - .20x$.

Substituting the mean distress score for unmarried women (37.34) and solving for x yields a DAS score of 114.36. A formula used by Neter, Wasserman, and Kutner (1985) yields 95% confidence intervals of $\pm.60$ for this figure. This estimated DAS score is modestly but significantly higher than the mean DAS for the married women (111.79), $t(378) = 2.67, p < .01$. Thus, it appears that, within this sample, married women need a better than average marriage to be as low in psychological distress as unmarried women, although the effect is not large.

Hierarchical Multiple Regression Analysis Examining the Contribution of Social Support to Women's Distress

A hierarchical multiple regression analysis was conducted to assess the contributions of key variables to the women's level of psychological distress. Psychological distress was the dependent measure with history of cancer, marital status, time since cancer diagnosis, and spouse and female relative support variables as predictors. We sought to use the entire sample for this analysis, but this required a solution to the problem of women without a history of cancer not having scores for the variable of time since diagnosis and unmarried women not having scores for the spouse support variables. These are important considerations. On average, the women in our sample were relatively long-term survivors of cancer, with a mean length of time since diagnosis of 8.26 years ($SD = 6.51$ years). Clearly, we could not consider never having been diagnosed with cancer as 0 time since diagnosis: Presumably there is an immediate increase in distress after a diagnosis, but this effect might dissipate with time. Similarly, our analyses had already shown that women in unsatisfactory marriages were worse off than unmarried women, and we could not assume that being unmarried was equivalent to having a husband and perceiving no positive or negative support from him.

Cohen and Cohen (1983) suggested a solution to this problem using nonsense coding of time since diagnosis for women without a diagnosis of cancer and of spousal support for the unmarried women and dummy coding of breast cancer and marital status. It does not matter what time since diagnosis is assigned to women who have not been diagnosed with cancer if we consider this variable only in interaction with breast cancer status coded 0 for never diagnosed and 1 for having had a diagnosis. Similarly, it does not matter what scores for support from husbands are assigned to unmarried women if we consider these variables only in interaction with marital status coded 0 for unmarried and 1 for married.

As a first step in a multiple regression analysis, we entered the demographic variables: age, cancer status, marital status, and the modified Time Since Diagnosis $\times$ Cancer Status variable. As seen in Table 4, only 2% of the

Table 4
Hierarchical Regression Examining Predictors of Psychological Distress for Women at Risk for Breast and Ovarian Cancer

	Psychological distress ($n = 356$)		
Predictor variables	ΔR^2	β	B
Step 1: demographic variables	.02		
Age		$-.03$	-0.03
Breast cancer status		$.20^{**}$	3.65
Marital status		$-.03$	-0.61
Time since diagnosis		$-.17^*$	-0.28
Step 2: support variables	.09***		
Female relative positive support		$-.11$	-0.32
Female relative negative support		.06	0.86
Spouse positive support		.14	0.31
Spouse negative support		$.29^{***}$	3.58
Full predictor set	.11***		

$^*p < .05.$ $^{**}p < .01.$ $^{***}p < .001.$

variance was accounted for by this model; cancer status and time since diagnosis significantly contributed to distress. In the next step, we entered the support variables: female relative and the modified Spouse Support × Marital Status variables. As can be seen in Table 4, there was a significant increase in the amount of variance accounted for by the model, but the only variable making a significant independent contribution to psychological distress was unsupportive behaviors from spouses.

Differences Between Spouses and Sisters as Sources of Cancer-Specific Support

Table 5 presents means and standard deviations of married women's ratings of their spouses and sisters at risk for cancer as providers of cancer-specific support, distinguishing between satisfactorily and unsatisfactorily married women. A series of 2 × 2 × (2) ANOVAs were conducted, with history of cancer and marital satisfaction as the between-

Table 5
Mean Ratings of Cancer-Specific Support Received From Spouses and Sisters for Women in Distressed Marriages and in Satisfying Marriages

	Women in distressed marriage				Women in satisfying marriage			
	Spouse		Sister		Spouse		Sister	
Likert scale item	M	SD	M	SD	M	SD	M	SD
Discuss breast cancer with him/her[a]	2.65	0.96	2.58	0.93	2.96	0.86	2.68	0.90
Satisfaction with these discussions[b]	2.94	0.92	3.00	1.02	3.33	0.81	3.27	0.85
Importance of his/her opinion in your undergoing BRCA1 testing[c]	2.49	1.20	2.24	1.28	3.13	1.05	2.42	1.24
Importance of his/her opinion in making decision about reducing risk[d]	2.59	1.17	2.43	1.23	3.32	1.03	2.51	1.18

Note. Subsample size ranges from 65 to 84 for paired *t* tests of women in distressed marriages and from 156 to 172 for paired *t* tests of women in satisfying marriages, reflecting the fact that not all women had living sisters.
[a]Significant effect for marital satisfaction ($p < .05$) and for spouse versus sister ($p < .05$). [b]Significant effect for marital satisfaction ($p < .001$). [c]Significant effect for marital satisfaction ($p < .01$), spouse versus sister ($p < .001$), and the interaction ($p < .001$). [d]Significant effect for marital satisfaction ($p < .01$), spouse versus sister ($p < .001$), and the interaction ($p < .05$).

participants independent variables and husband versus sister as the within-participant variable for each cancer-specific support variable. In terms of discussions about cancer and cancer risk, there were significant main effects for marital satisfaction, $F(1, 251) = 4.83, p < .05$; women in satisfying marriages reported more discussions than women in dissatisfied marriages. A significant within-participant effect for source of support, $F(1, 251) = 6.25, p < .05$, reflected the marital relationship overall being the site of more discussions. It is notable that there was not a significant interaction between marital satisfaction and source of support. Instead, the only significant interaction was between cancer status and source of support, $F(1, 251) = 3.76, p < .05$. Follow-up paired t tests revealed that women with a history of cancer reported discussing their risk of cancer more with their spouses than with their sisters, $t(125) = -3.61, p < .001$, whereas those without a history of cancer did not differ in the frequency of discussions with spouses and sisters.

Regarding satisfaction with discussions about cancer, women with a history of cancer, $F(1, 217) = 6.96, p < .01$, and who were in a satisfying marital relationship, $F(1, 217) = 13.37, p < .001$, were significantly more satisfied with discussions about cancer regardless of whether the discussions were with their spouse or their sister. There were no significant interaction effects between marital satisfaction and source of support.

When examining the importance women place on opinions regarding ways to reduce cancer risk, main effects were found for marital satisfaction, $F(1, 246) = 9.91, p < .01$, and source of support, $F(1, 246) = 34.54, p < .001$. However, these effects need to be interpreted in light of the interaction found between marital satisfaction and source of support, $F(1, 246) = 16.10, p < .001$, and history of cancer and source of support, $F(1, 246) = 6.86, p < .01$. A main effect suggested that for women with a history of cancer, $t(121) = -7.18, p < .001$, and without such a history, $t(140) = -4.13, p < .001$, spouses' opinions were significantly more important than sisters' opinions. However, the interaction effect revealed that only women in satisfying marriages actually reported that their spouses' opinions regarding reducing risk were

more important than those of their sisters, $t(169) = -8.88, p < .001$.

Main effects were also found for marital satisfaction, $F(1, 248) = 9.80, p < .01$, and source of support, $F(1, 248) = 28.05, p < .001$, when examining the importance women place on their support providers' opinions regarding undergoing genetic testing for risk of breast and ovarian cancer. Again, however, these effects must be qualified by a significant interaction between marital satisfaction and support provider, $F(1, 248) = 6.64, p < .05$. Also again, paired t tests indicated that only women in satisfying marriages reported that their spouses' opinions regarding genetic testing were significantly more important than those of their sisters, $t(171) = -7.17, p < .001$.

Discussion

The results of the present study have both substantive and practical implications, and the manner in which marital satisfaction and spousal support were considered in the context of a sample in which not all women were married has broader methodological and theoretical implications. Yet, before considering these implications, the limitations of this study should be reiterated. This is a cross-sectional study of a self-selected and socially advantaged sample of women at high risk for breast and ovarian cancer, assessed at a time when they knew genetic testing would soon be available. There have been other indications that persons who participate in genetic studies, and who seek genetic testing, are socially advantaged, and that they self-select for ability to cope with the potentially threatening results of genetic testing (Codori, Hanson, & Brandt, 1994; Codori, Slavney, Young, Miglioretti, & Brandt, 1997; Coyne, Weber, & Sonis, 1999). This is not a representative sample of American women. Our largely middle-aged sample tended to be married, and the women who were married tended to be in satisfactory first marriages of relatively long duration. The sample was also high in education and income. It could be that their marital quality and high levels of support are critical determinants of their lack of distress or morbidity despite their familial risk for cancer, but other resources could account for their positive adjustment. As genetic testing becomes more widespread in the community, it will be important to compare our registry sample of

women with those in community clinical settings who seek testing with respect to social support as well as other variables. Most of what is known about psychosocial aspects of genetic testing comes from studies of women who have enrolled in hereditary cancer registries and who receive testing in the context of research protocols approved by institutional review boards. There has been concern that, as testing becomes more widespread, there will be important shifts in who is offered genetic testing and who receives it and under what circumstances (Coyne et al., in press; Coyne et al., 1999). Comparisons between registry samples, such as the present one, and community samples are important not only for determining the comparability of psychosocial resources among the two groups but also for establishing whether the relations among variables observed in registry samples actually explain the relative well-being of these women as a group.

For the purposes of the present discussion, the women's relatively low mean levels of distress and high levels of marital satisfaction in our sample should be taken into account in interpreting correlational and regression analyses. When we discuss women as having greater distress as a result of perceiving less social support, we are interpreting findings from a sample in which overall levels of distress are low. We have noted that even among maritally dissatisfied women, psychological distress remained below the clinical cutpoint on the HSCL-25. Also the marital stability and relatively high marital satisfaction of these women should be kept in mind in discussing marital variables. In dividing the married women into satisfied and dissatisfied groups, we were careful to use established cutpoints for marital adjustment. Had we used a median split, we would have considered many women as maritally dissatisfied who were decidedly not so by normative standards.

We applied some regression techniques that allowed us to make comparisons between married and unmarried women that took into account the marital satisfaction of the married women. However, we had no equivalent measure for the unmarried women. It might seem that the unmarried women's satisfaction with their marital status should also be taken into account. Yet the one study we could find that assessed unmarried women's satisfaction with their status failed to find it to be related to their

well-being (Gove & Zeiss, 1987). Apparently, satisfaction with not being married among the unmarried is not analogous to marital satisfaction among married women.

However, even keeping in mind potential limitations on the generalizability of these results, some important points can be made. In much of the social support literature, there has been an implicit assumption that people have a set amount of interpersonal needs that can be satisfied in different patterning of relationships and with support from different persons. Historically, this has been termed the "fund of sociability" idea (see Weiss, 1968, for a review). On this basis, it might be assumed that women who lacked a spouse or whose spouse was unsupportive would seek compensatory support from female relatives. Plausible though this notion may be, we found no evidence for it and considerable evidence against it. Indeed, support from the spouse was positively correlated with support from a close female relative, and women in satisfactory marriages actually perceived *more* support from female relatives than did unmarried women or women in unsatisfactory marriages. In this study, women in dissatisfied marriages still discussed their risk status with their husbands more than with sisters. There are a number of possible interpretations of these findings. It may be that perception of support is more of a personality variable than is generally recognized either as a result of personality determining perception of support or distress mainly determining perception of support rather than the perceived availability of support affecting level of distress. This intrapersonal interpretation has been favored by Sarason, Pierce, and Sarason (1990), among others. Alternatively, it could be that marital difficulties and accompanying distress alienate other sources of support or reduce the women's access to it. Finally, satisfactory marriages may facilitate positive social involvement outside the marriage. Such competing hypotheses need to be evaluated using sources of data other than the women themselves, notably others' perceptions of how available and supportive they are of the women and how frequent and satisfying their interactions are with the women.

In terms of cancer-specific support and decision-making processes, both sisters and husbands are important and involved in discussions with these women. However, husbands

appear to play a somewhat more important role than sisters despite the women's shared familial risk status. As in the general patterning of findings in this study, this statement needs to be qualified with respect to marital adjustment. Women in unsatisfactory marriages discuss their risk status more with their husbands than with sisters, although their husbands have diminished influence.

Our sample consisted entirely of women deemed at high risk for breast cancer on the basis of personal and familial history. We examined both personal history of cancer and length of time since diagnosis as influences on well-being, but social support processes seemed to be more important influences on well-being. One might be tempted to argue that, because all women in the sample were at high risk for cancer, we underestimated the influence of this status on well-being. Yet it must be kept in mind that the sample was low in distress relative to various comparison samples (Coyne et al., in press). Unless we wish to argue that high-risk status per se somehow reduces distress, we need to acknowledge the importance of psychosocial influences on these women's well-being. In particular, husbands proved to be primary influences on the women's distress levels and primary sources of cancer-specific support. Within the sample as a whole—considering both married and unmarried women—unsupportive behavior by the husband's was the only independent connection between social support processes and distress, despite other significant bivariate relations between support and distress. Finally, married and unmarried women had similar levels of distress, but additional analyses showed that married women had to have modestly better than average marriages to be equivalent to unmarried women.

Implications for Application and Public Policy

These results have a number of practical implications for efforts to educate and counsel high-risk women for the prospect of genetic testing for risk of breast and ovarian cancer in research settings. It appears that husbands of these high-risk women are key influences on their well-being and providers of cancer-specific support as well as active participants in the women's decision-making processes. The women should be given opportunities for involving husbands in the preeducation and counseling process to ensure that the men's participation in the women's decision making is informed and appropriate. It has previously been recognized that genetic testing is a family as well as an individual issue, but much of the emphasis has been on blood relatives who share a high-risk status and for whom other family members' test results are potentially informative of their own risk status. However, our data indicate that husbands are at least as influential as the women's closest at-risk female family member. Our data were collected before genetic testing was actually being made available to these women. Once results begin to be received by the women and their family members, husbands could become even more important. Women may be less able to seek support from female relatives who are struggling with their own discovery that they have an altered gene associated with heightened risk for cancer. Furthermore, women who find that they do not have such an altered gene may still be distressed about the process of genetic testing but feel guilty and ineligible to compete for support with female relatives who are found to have an altered gene. Clinical experience with genetic testing for Huntington's disease suggests that support from close but not genetically related relatives can be crucial at the point of risk disclosure. It is reassuring that the husbands of the high-risk women in our sample are already involved as support providers. However, all of these points need to be qualified with reference to women in the study being self-selected members of a hereditary cancer registry. The results we have presented here and the implications we have drawn may not apply to women from the community expressing an interest in genetic testing.

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**THE EUNICE AND IRVING LEOPOLD ANNUAL
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UNDERSTANDING RISK PERCEPTION AMONG WOMEN ATTENDING THE
CANCER RISK EVALUATION PROGRAM

M. W. Racioppo, K. Armstrong, L. K. Kruus, & J. C. Coyne

Women with a family history of breast cancer who seek risk counseling are widely portrayed as overestimating their risk of breast cancer and as being a psychologically vulnerable population. However, the limited research literature on which this stereotype is based is characterized by a number of methodological problems. Namely, there are inconsistencies in the measures of perceived risk that have been employed and they typically do not have established empirical validity. Furthermore, inferences about the level of psychological distress among these women have been made in the absence of appropriate normative comparisons. The present study addressed these problems by including multiple measures of risk perception and by introducing a direct comparison between levels of distress in the study sample and what has been found in other diverse populations. The sample consisted of 348 women attending a high-risk cancer clinic. All women completed three conventional self-report measures of perception of lifetime breast cancer risk: 1) a visual analog scale anchored with numerical percentages; 2) a 5-point Likert-scale anchored with adjectives from very low to very high; and 3) a 5-point Likert- scale involving self-comparison to the average woman. They additionally completed the intrusion subscale from the Impact of Event Scale; Horowitz, Wilner, & Alvarez, 1979) as a measure of distress. Finally, an estimate of objective risk of breast cancer was calculated using the Gail model. The women were found to overestimate their risk of breast cancer relative to the objective estimate. Yet, they perceived themselves as at lower risk than the average woman, and there was only a modest intercorrelation among the alternative measures of risk. Perceived risk was only modestly related to distress, and mean levels of distress were lower than relevant comparison samples. These results call into question the convergent validity of existing measures of risk perception and add to concerns about the substantive interpretation of self-report risk perception data. Although counter to existing stereotypes, findings concerning psychological distress among these women are consistent with other emerging findings that high-risk women are not psychologically distressed as a group.

Husbands of Women Anticipating Genetic Testing for Risk of Breast Cancer

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Being at high risk for cancer, and being offered genetic testing to ascertain that risk, have been viewed as experiences that affect family members as well as the individual. Disclosure of a woman's positive mutation status is seen as particularly threatening to family members. Spouses are thought to be especially at risk, as it is generally assumed that couples respond as a unit to illness stressors. However, the literature generally confounds patient status with gender, so that associations between patient and spouse responses may be limited to situations in which the patient is male and the spouse is female. The present study investigated the adjustment of women participating in genetic testing, and of their husbands. A total of 202 women from a cancer registry and their husbands completed questionnaires before cancer risk counseling. The questionnaire included the Hopkins Symptom Checklist - 25 item version (Derogatis, Lipman, Rickels, et al., 1974) assessing psychological distress, two 5-point scales assessing breast cancer worry and functional impairment due to worry, cancer risk perception described as a percentage, and other measures of functioning. On average, neither women nor their husbands reported clinical levels of distress. In contrast to the prevailing assumptions of the literature, there were no significant correlations between female participants' and their husbands' perceptions of cancer risk, psychological distress or worry. Further, husbands reported less psychological distress and lower perception of wive's risk of breast cancer than did women participants (both significant at $p < .01$). The lack of association between women-participant and husband responses to testing stands in sharp contrast to the accepted notion that couples function as a unit in response to illness risk. Despite discrepancies between partners' responses, findings from the current study suggest that husbands play the primary role in social and decision-making support for their wives. These data add to cautions about interpersonal models of couples coping with stress that fail to be explicit about the role of gender.

Racioppo, M.W., & Coyne, J.C. (2001, October). Husbands of women anticipating genetic testing for reisk of breast cancer. Paper to be presented at the American Psychological Association's Women's Health Outcomes Conference. Washington, D.C.

Distress in anticipation of BRCA1/2 Testing: Some relevant comparisons
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Existing data suggest that women receiving testing for the *BRCA1/2* mutations are self-selected for psychological adjustment and that the revelation of positive risk status does not have lasting negative psychological consequences. Nonetheless, there is a stereotype that women with familial risk of breast cancer are psychologically vulnerable and that genetic testing carries substantial risk of psychological morbidity. This is in part based on selective attention to studies which do not employ standardized measures of distress or which neglect to make relevant population comparisons. The present study examined self-ratings of distress associated with various threats, including: (a) being a member of a high-risk family; (b) being offered testing; and the possibility of testing (c) negative or (d) positive for a gene mutation. Additionally, the study examined the level of distress associated with the possibility of developing breast cancer among women without a breast cancer history, and distress related to receiving a breast cancer diagnosis was examined among those with a history of the disease. Moreover, the association of this threat-related distress with well-validated measures of personal and social functioning, general psychological distress, and interference with daily life was explored. Participants were 470 women (45% with a personal history of cancer) involved in hereditary cancer studies at the University of Pennsylvania Cancer Center. Analyses revealed a distress by breast cancer status interaction ($p < .05$). Specifically, for women with a history of breast cancer, the level of distress associated with receiving a diagnosis of breast cancer was greater than all other threats. In contrast, for women without a history of breast cancer, level of distress related to testing positive for *BRCA1/2* gene mutations was greater than all other sources of distress. Importantly, for both groups of women, results also suggest that elevations in these concerns are not associated with clinically significant distress or interference with daily life. These findings add to the weight of evidence that genetic testing for *BRCA1/2* mutations may not be as distressing as the literature presents. Instead, testing may be useful as a tool to help women determine their risk for future decisions (e.g., prophylactic surgery). Indeed, testing may help to resolve the chronic stress associated with being a member of a high-risk family and being at personal risk for cancer.

DISTRESS IN ANTICIPATION OF *BRCA1/2* TESTING: SOME RELEVANT COMPARISIONS

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Existing data suggest that women receiving testing for the *BRCA1/2* mutations are self-selected for psychological adjustment and that the revelation of positive risk status does not have lasting negative psychological consequences. Nonetheless, there is a stereotype that women with familial risk of breast cancer are psychologically vulnerable and that genetic testing carries substantial risk of psychological morbidity. This is in part based on selective attention to studies which do not employ standardized measures of distress or which neglect to make relevant population comparisons. The present study examined self-ratings of distress associated with various threats, including: (a) being a member of a high-risk family; (b) being offered testing; and the possibility of testing (c) negative or (d) positive for a gene mutation. Additionally, level of distress associated with the possibility of developing breast cancer was examined among women without a breast cancer history, and distress related to receiving a breast cancer diagnosis was examined among those with a history of the disease. Moreover, the association of this threat-related distress with well-validated measures of personal and social functioning, general psychological distress, and interference with daily life was explored.

Participants were 470 women selected from the Hereditary Breast and Ovarian Cancer Study by the University of Pennsylvania Cancer Center and the University of Michigan. The sample ranged in age from 19 to 86 ($\underline{M}$ = 48.5) and was predominantly Caucasian, well educated, married, and of high SES. Forty-five percent of women had a history of breast cancer ($\underline{M}$ years since diagnosis = 8.24).

Analyses revealed a distress by breast cancer status interaction (p < .05). Specifically, for women with a history of breast cancer, the level of distress associated with receiving a diagnosis of breast cancer was greater than all other threats, and distress associated with testing positive for the *BRCA1/2* gene mutations and elevated familial risk did not differ significantly. The level of distress associated with each of these threats was significantly greater than distress related to being offered testing. Level of distress associated with testing negative for the mutations was significantly less than that related to all other threats. In contrast, for women without a history of breast cancer, level of distress related to testing positive for *BRCA1/2* gene mutations was greater than all other sources of distress. The levels of distress were as follows (greatest to lowest): high familial risk, the possible development of breast cancer, being offered

testing, and testing negative for the gene mutation. Yet, the level of interference from breast cancer worry was not significantly different from level of distress associated with a negative test result and that of being offered testing. Importantly, for both groups of women, results also suggest that elevations in these concerns are not associated with clinically significant distress or interference with daily life.

These findings add to the weight of evidence that genetic testing for *BRCA1/2* mutations may not be as distressing as the literature presents. Instead, testing may be useful as a tool to help women determine their risk for future decisions (e.g., prophylactic surgery). Indeed, testing may help to resolve the chronic stress associated with being a member of a high-risk family and being at personal risk for cancer.

APPENDIX D: PERSONNEL LIST FOR DAMD17-96-6157

PERSONNEL LIST FOR DAMD17-96-1-6157

July 1996 - June 2001

Coyne, James
Bouvrette, Sean
Hamby, Julie
Lutz, Catherine
Schaefer, Nancy
Jordan, Lucy Portner
Krone, Carolyn Hill
Connelly, Judy
Singer, Kathleen
Dong, Fang
Marchel, Elizabeth
Zelenski, John
Bevis, Claudia
Cranford, James
Chin, Carol
Park, Joonhyung
Weber, Barbara
Calzone, Kathleen
Colligan, Teresa Ward
Davis, Alexa
Greshock, Joel
Adams, Barbara
Racioppo, Melissa
Kruus, Linda
Kagee, Ashraf
Palmer, Steven
Hearn, Joseph
McDermott, Nicholas
Trucco, Elissa